The potential role of human rights and the right to privacy in the context of English care homes for older people
multiple perspectives

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The potential role of human rights and the right to privacy in the context of English care homes for older people: multiple perspectives

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Thesis submitted in fulfilment of the requirements for the degree of Doctor of Philosophy

November 2019

Institute of Gerontology
King's College London

Abstract

This thesis explores the potential role of human rights and the right to privacy in care homes for older people in England. It does so from the perspective of residents, their relatives, care home managers, care workers and the Care Quality Commission (CQC) – England's care service quality regulator. The findings rely on qualitative interviewing techniques, document analysis and simple quantitative research methods.

Care homes for older people in England are increasingly required to consider the human rights of residents and staff on the basis of a human-rights-oriented legal and regulatory framework. This framework is developing in the wider context of a growing international consensus on shared responsibility for human rights amongst public entities, private entities and individuals, debate on how to protect the rights of older people and people with disabilities, and ongoing concerns about quality in English care homes. Under British human rights law, the government and its representatives still have the main responsibility for human rights – the rights of all human beings. However, most of England's care homes are privately owned and run. When applied to care homes, the human-rights-oriented legal and regulatory framework marks a shift in the traditional conceptualisation of human rights in England. This poses questions about the purpose of and need for such an approach, and its practical implications for care homes and their communities.

This thesis develops a typology of perspectives on the potential role of human rights in care homes for older people by drawing on the study's findings and the socio-legal and social policy literature. It reveals multiple approaches to and views on the topic, and highlights the challenges in realising the potential roles identified. Furthermore, it argues that the topic of human rights in English care homes for older people is an emotive one. Perspectives on its potential role are shaped by social, political and personal realities and the experiences of individuals in care home communities.

The study suggests that future international and national debates on the human rights of older care home residents should not assume a consensus on the potential role of human rights in care homes. Furthermore, any effort to integrate human rights into care homes should consider the complicated realities of people who live in, work in or visit these places and the implications of these on such efforts. The findings on the purpose of the right to privacy and its implications for care practice provide a framework for respecting this right in care homes.

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Acknowledgements

This thesis would not have been possible without the care home owners, managers and staff and the residents and their family members who took part. I would like to thank them all warmly for their interest in my research, for trusting me, for inviting me into their homes and for courageously sharing stories from their life and work. I would also like to thank the CQC for their encouragement and openness in engaging with me on their human rights work, which was invaluable to the research process.

My supervisors – Professor Jill Manthorpe and Professor Anthea Tinker – provided me with the perfect balance of trust, support and independence. Their suggestions and input were incredibly helpful. Their doors were always open to me, whether I needed to discuss any concerns or have a friendly chat. I am very grateful to have had them by my side on this journey.

I would also like to thank Professor Shereen Hussein, Dr Annette Rid, Professor Karen Glaser and Dr Octavio Ferraz, who supervised the early stages of this thesis and helped me to shape the project. Professor Ian Kessler examined this thesis at the upgrade stage, and I thank him very much for his constructive feedback. Thank you very much also to Laura Ripper, who copy-edited the final thesis.

I would like to express my gratitude to Professor Julienne Meyer and Tom Owen from City University of London and Professor Belinda Dewar from the University of the West of Scotland, who introduced me to the My Home Life movement. I had valuable discussions with them at several stages of my studies and they allowed me to tap into their experience and connections. Many of the tools used in the interviews were developed by them, and the research profited from this immensely.

The community of PhD students at King's was something I would not have wanted to miss. Dr Katharine Orellana, Dr James Fletcher and Dr Giulia Cavaliere helped me at many stages of my work, answering questions and sharing their experiences. Thank you!

Without my family this PhD would not have been possible. My parents Gisela and Dr Harald Mosler, my husband Ian and my sister Margarethe Schlemmer put up with an emotional rollercoaster for years and supported me without question in all aspects of life. My daughter Audrey was very patient, and her cuddles were the best thing in the world to keep me smiling throughout the PhD. My father-in-law, Mick Green, took the time to read a draft of this thesis and my mother-in-law, Denise, helped me during the lengthy school holidays before submission. I cannot thank my entire family enough. Sadly, my grandparents, Theresia and Eduard Wammetsberger and Hildegard and Dr Horst Mosler, did not live to see the end of my studies, but this PhD is ultimately for them and for all the other older people in our society.

List of abbreviations

ADLs	Activities of Daily Living
BAME	Black, Asian and minority ethnic
CQC	Care Quality Commission
CEDAW	Convention on the Elimination of All Forms of Discrimination against Women
CoE	Council of Europe
DoLS	Deprivation of Liberty Safeguards
ECHR	European Convention for the Protection of Human Rights and Fundamental Freedoms
ECtHR	European Court of Human Rights
EU	European Union
FAIR approach	A human rights approach standing for the principles of Facts, Analyse rights, Identify Responsibilities, Review actions
FREDA principles	The principles of Fairness, Respect, Equality, Dignity, Autonomy
GDPR	The EU General Data Protection Regulation
HRA	Human Rights Act 1998
ICCPR	International Covenant on Civil and Political Rights
ICESCR	International Covenant on Economic, Social and Cultural Rights
ICROP	International Convention on the Rights of Older Persons
KLOEs	Key Lines of Enquiry
LGBTQ+	Lesbian, gay, bisexual, transsexual, questioning and other
MCA	Mental Capacity Act 2005
MoU	Memorandum of Understanding
NCSC	National Care Standards Commission
NHS	National Health Service
OEWGA	Open Ended Working Group for the purposes of strengthening the protection of the human rights of older persons
UDHR	Universal Declaration of Human Rights
UK	United Kingdom
UN	United Nations
UNCRPD	Convention on the Rights of Persons with Disabilities
UNGPs	United Nations Guiding Principles on Business and Human Rights

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PART I: INTRODUCTION and the RESEARCH CONTEXT

1 Introduction

This study used qualitative research methods to capture multiple perspectives on the potential role of human rights in care homes for older people in England. Interviews were conducted with people working in, living in and visiting care homes, and the role of human rights in the Care Quality Commission's (CQC's) regulatory framework for care homes was analysed. The findings were then integrated in this thesis. The study further explores the practical implications of residents' right to privacy in care homes.

The proliferation and potential effects of age-based discrimination (ageism) against older people, including abuse and violence, has attracted attention from human rights advocates in recent years (McHale, 2012; Poffé, 2015). Meanwhile, calls for an International Convention on the Rights of Older Persons (ICROP) have been growing louder (Meenan et al., 2016; Kesby, 2017). The role of long-term care in general, and residential care in particular, has been debated in the literature and in national and international policy. Firstly, the very existence of care homes for older people has been criticised as a symptom of ageist economic and social systems, with some arguing that it creates "structured dependency" amongst older people (Townsend, 2006). In general, opportunities for "ageing in place" – staying at home for longer – are considered preferable to life in a care home. Secondly, the nature of care homes as institutions has attracted widespread concern about violations of residents' human rights, including ageism and related harmful behaviour (Buttigieg et al., 2018 p. 499). A growing body of research highlights the 'inherent human rights related risks' of care homes (e.g. Meenan et al., 2016; Cahill, 2017; Lloyd-Sherlock et al., 2018; Taghizadeh-Larsson and Jönson, 2018). Despite long-term efforts to secure quality in care homes across England, negative perceptions have been fostered by recent high-profile abuse scandals (Manthorpe and Samsi, 2016). Therefore, there are widespread negative perceptions when it comes to residents' human rights.

The emerging "human rights approach to ageing" (Kesby, 2017; Love and Lynch, 2018) aims to ensure that older people (including older residents of care homes) are no longer perceived as vulnerable objects of charity, but as holders of human rights (Kesby, 2017 p. 386). Under the Care Act 2014, local authorities in England must promote the well-being of people who need care and support; they must protect their dignity and protect them from abuse and neglect (Care Act 2014, Section 1(1) and Section 1(3)(g)). These developments, along with ongoing concerns about the effects of institutional care on residents, make human rights an acutely important topic in care home research.

Since the Human Rights Act 1998 (the HRA) was adopted in England, human rights have increasingly been infiltrating regulatory regimes (Klug, 2015; Gearty, 2016). These include government tools and instruments that set standards for the quality of English care homes (Meenan, 2016). For example, the CQC – England's care quality oversight body – has adopted a human rights approach to regulating care homes. Therefore, human rights are now part of the CQC's understanding of service quality. Section 73 of the Care Act 2014 enables publicly funded care home residents to hold providers – even private ones – legally accountable for violations of their human rights. This marks an important shift in the understanding of protecting human rights: a duty that has traditionally rested with the state. As a government organisation, the National Health Service (NHS) has clear responsibilities regarding human rights; however, for the largely privatised care home market in England, a human rights framework is an interesting development. Recent research (Trigg, 2018 p. 114) has suggested that advocacy and stakeholder groups have steered the current regulatory regime for English care homes towards the human rights approach to ageing. In this context, human rights research in and with care homes is relevant. It is especially pertinent when focusing on the practical implications of human rights for care service provision.

There is still a lack of academic literature on "norm specification": the necessary environmental, behavioural and other factors that lead to human rights being protected and respected inside care homes. This is especially the case for the right to privacy, which is often salient in institutional contexts (Emmer DA Green et al., 2019). A growing body of research on quality of life and quality of care has involved care home providers, residents and staff, and residents' families. However, no studies have yet captured multiple perspectives on the potential role of human rights in care homes for older people in the context of the current regulatory framework. If the concept of human rights is to make a positive contribution to the lives of residents and others in the care home system (as envisaged by human rights advocates), it is urgently necessary to uncover the perspectives of residents as "rightsholders" and staff as "duty-bearers". This standpoint was the motivation for this thesis. Whilst considering the potential role of human rights from the regulator's point of view, this thesis emphasises the perspectives of people in care homes. To enhance understanding of the implications of human rights for care home practice, the thesis also explores the meaning of the right to privacy from the viewpoint of the CQC, care home residents, relatives and staff.

1.1 Defining human rights and the right to privacy

1.1.1 Human rights

Any reliable human rights research must clearly define the concept for the research project and declare any assumptions made in that definition (Coomans et al., 2009 pp. 14–17). The concept of

human rights is a matter of multiple, often opposing perspectives, despite its prominent use in advocacy, law and regulation. Its definition and content have long been subjects of debate amongst sociologists, politicians, philosophers, lawyers and anthropologists. This has resulted in a broad range of definitions, which frequently blur the boundaries between the sources, content, features, foundations and use of human rights (Cruft et al., 2015).

As a working definition of human rights, this thesis refers to the "universal declaration model of human rights" (Donnelly, 2013). This delimits the sources, content and key characteristics of the concept. According to this model, human rights are *moral entitlements* ("norms") needed for human life with dignity (Donnelly, 2003 p. 14). At the same time, they are *legal entitlements*, through which such moral claims can be enforced in court. All human beings have human rights, irrespective of their age, gender, origin or other personal characteristics. The rights are inalienable and can be limited only on the basis of international and national law.

A defensible, internationally recognised list of legal (and, thus, normative) human rights is enshrined in the Universal Declaration of Human Rights 1948 (UDHR) and the international, national and regional documents that follow the UDHR (Donnelly, 2003 p. 15). The UDHR was adopted by the United Nations (UN) on 10 December 1948 in response to the atrocities committed by states during World War II. It is widely accepted as the founding document for the "modern international human rights regime" of documents and institutions that protect human rights (Cruft et al., 2015). The United Kingdom (UK) has ratified all the UN conventions and the European Convention for the Protection of Human Rights and Fundamental Freedoms 1950 (henceforth the European Convention on Human Rights [ECHR]), a regional human rights document. Thus, the UK is bound by these conventions under international law. Table 1.1 presents the rights and freedoms contained in the ECHR.

Table 1.1 Human rights in the ECHR

Table 1.1: The human rights contained in the European Convention on Human Rights		
Article 2: The right to life	Article 3: Prohibition of torture	Article 4: Prohibition of slavery and forced labour
Article 5: The right to liberty and security	Article 6: The right to a fair trial	Article 7: No punishment without law
Article 8: The right to respect for private and family life	Article 9: Freedom of thought, conscience and religion	Article 10: Freedom of expression
Article 11: Freedom of assembly and association	Article 12: The right to marry	Article 13: The right to an effective remedy
Article 14: Prohibition of discrimination	Article 1 Protocol 1: Right to peaceful enjoyment of possessions	Article 2, Protocol 1: Right to education

Thus, in this thesis, "human rights" are the rights and freedoms contained in the UDHR, the related UN conventions and the ECHR. The content of these instruments reflects an international legal and moral consensus on which rights should be considered *human* rights (Donnelly, 2013).

Three further assumptions are made regarding human rights in this thesis. Firstly, it adopts a constructivist approach to human rights, as proposed by some proponents of the universal declaration model (e.g. Nickel 2007; Donnelly, 2013). It assumes that human rights are socially constructed and may be translated differently in diverse cultures and contexts. This allows for the flexibility to hear multiple perspectives on the meaning of human rights in practice, which are rooted in individuals' personal experiences, social contexts and relationships with others (Donnelly, 2013).

Secondly, this thesis assumes that the concept of human rights is a relational one: it unfolds in the relationships and interactions between individuals in everyday life (Nedelsky, 1993, 2008; Minow and Lyndon Shanley, 1996; Herring, 2017, 2014, 2013a). Human rights are often associated with the political philosophy of liberalism and its underlying values of individualism, autonomy and liberty (Steiner et al., 2007 p. 59). This association between liberal thinking and human rights has led to criticism from feminist care ethicists (e.g. Tronto, 1993; Herring, 2014; Held, 2015). Proponents of care ethics have frequently criticised how human rights language is used in the context of public policy and advocacy, at times in connection with care for older people and people with disabilities. They argue that this language fails to recognise the "inherent vulnerability" of the human being, the centrality of care in human existence and the importance of relationships with others (Held, 2015). It is often argued that the liberal idea of human rights envisages an "able-bodied rational rightsholder", who can claim their rights and disregard the needs of others (Nedelsky, 2011). However, some relational conceptions of human rights are based on the belief that human rights construct relationships "of power, responsibility, trust and obligation" between people (Nedelsky, 2008 p. 139) and come to life when people interact. This thesis does not aim to develop the theory of this approach to human rights. Rather, it aims to consider participants' perspectives on human rights in care homes in the light of their experiences and views of care homes in general and the complex relationships between people inside and outside the care home. It was assumed that their perspectives had been shaped by such experiences and relationships and, thus, that their perspectives were interlinked and interdependent.

Thirdly, this thesis explores the *potential* role of human rights in care homes. It assumes that, from a legal standpoint, the obligation to protect human rights still lies primarily with the government and public authorities rather than with private companies and private individuals, including privately

operated care homes and their staff. However, the thesis also contends that a "trickling-down process" of imposing human rights obligations on care homes is taking place in England. This is happening through the current regulatory regime, including the Care Act 2014 and the CQC's regulatory framework, and through public debate on the inherent human rights risks posed by institutional care. This thesis aims to capture stakeholders' perspectives on this process.

1.1.2 The right to privacy

Many human rights scholars consider the right to privacy to be a norm and a legal right – and, thus, essential for human dignity. The right to privacy refers to people's broad entitlement to be free from unlawful interference with their private and family affairs (Tugendhat, 2017). As a legal right, it is enshrined in Article 12 of the UDHR, which states: "No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation". Furthermore, Article 8 of the ECHR states: "Everyone has the right to respect for his private and family life, his home and his correspondence".

The legal right to privacy includes four inter-related yet distinct spheres: private life, family life, home and correspondence. As such, it is relevant to all areas of human activity in society (Scott et al., 2003). Respecting privacy forms part of the CQC's understanding of quality in care home services (see Chapter 11). Care home managers and staff must ensure that residents' privacy is respected at all times. A recent review of the evidence for good practice in respecting residents' right to privacy (Emmer DA Green et al., 2019) defines the dimensions of privacy that are relevant to providing direct care services. Building on this, the premise of this thesis is that in order to respect the right to privacy in care homes, it is essential to gain an in-depth understanding of the relevant dimensions of privacy. The right to privacy is explored in Chapters 11 and 12.

1.2 Defining care homes

The term "care home" typically refers to a location in which individuals live continuously (Commission on Residential Care, 2014) and receive care and support. In the UK, around 433,000 people live in a care home (LaingBuisson 2016: xxi). In England there are residential and nursing care homes, but in practice there is much overlap between the two types. Residential care homes dominate the sector: there are roughly 8,600 locations compared with 4,500 nursing home locations (ONS, 2018 p. 64). Residential care homes employ care workers, who support residents around the clock with activities of daily living (ADLs), including washing and dressing, and tend to all their physical and emotional needs (CQC, 2016). This provision is called "social care", a type of care that may also be provided by other care services; for example, in community locations.

Defining social care only by the activities it may involve does not sufficiently capture its relational dimensions. Care ethicists have provided theoretical definitions of caring, which are useful in this regard (e.g., Fisher and Tronto, 1991; Tronto, 1993; Sevenhuijsen, 2003; Herring, 2013b). For example, Herring (2017 p. 160) defines caring as follows: "[Caring is] the meetings of needs of another, in a way that respects them as a person, which involves acknowledging the responsibilities that come with caring and which must be understood in the context of mutual relationships". In this definition of caring as a relational activity, Herring does not differentiate between the carer and the cared for, but promotes the idea of caring relationships in which "both parties, maybe in different ways, meet the needs of each other and their interests and identities, becoming intertwined in an intimate relationship" (Herring, 2017 p. 160). In this thesis, care homes are considered to be "communities of people" in which caring relationships exist between individuals (see Chapter 3). This conceptualisation underlies the exploration of people's perspectives on human rights.

Nursing homes, or care homes with nursing, offer on-site healthcare from qualified nurses (CQC, 2016) in addition to social care. Beyond the traditional care tasks, all care homes are expected to provide residents with "hotel-like services", including meals, laundry and cleaning services, entertainment and activities (Emmer DA Green, 2017; Trigg, 2018). This thesis focuses on residential care homes, so the term "care homes" refers to this type only.

1.3 Defining older age

This thesis focuses on "older people". What constitutes older age is still the subject of debate, and academics have taken biological, sociological, cultural, self-identifying and chronological approaches to defining it. One of the challenges of doing so is the diversity within age groups.

Peter Laslett (1987), for example, divided older age into the third age and the fourth age; the former is a potential life phase of self-fulfilment, and the latter is one of decrepitude and death (Gilleard and Higgs, 2014). Others have developed sub-groups, such as "the young old, middle old and oldest-old" as a response (von Humboldt et al., 2014). In social identity theories, older age is treated as a matter of an individual's perception of herself and the processes of assimilation through social relationships (e.g. Sneed and Whitbourne, 2003). For public policy purposes (e.g. setting State Pension age), a chronological definition of older age may be adopted (Roebuck, 1979). At the UN level, old age is generally defined chronologically as people who are older than 60, although this definition is a matter of debate (Kesby, 2017).

The multiplicity of approaches to defining older age highlights the complexity of the concept. For methodological purposes only, this thesis uses a chronological definition of older people that is set

at 65 or older. This is in line with the definition used by the CQC and care home providers when describing the age groups they provide services to.

1.4 The significance of care homes in England

Erving Goffman's (1961) and Peter Townsend's (1962) early descriptions of care homes as "asylums" and "custodial institutions" that incarcerate residents prompted the anti-institutional literature and policies seen in recent decades (Johnson et al., 2012). This has contributed to "relegate[ing] residential institutions to the status of last resort" (Jack, 1998 p. 1) and promoting community-based alternatives, such as retirement villages or day-care centres (Johnson et al., 2012 p. 11). Furthermore, the Office for National Statistics (ONS) has estimated that around 2 million people in the UK are receiving informal care from family members rather than from care homes (Office for National Statistics, 2019). The care home market is often referred to as being in crisis due to a lack of funds and staff (see Chapter 3). Despite this, consumer research data (Competition and Markets Authority, 2018a; LaingBuisson, 2018) and demographic trending (ONS, 2018) suggests that care homes will continue to be important as England's society ages and people need more support with personal care and healthcare for extended periods (long-term care).

England faces challenges in providing long-term care for its ageing population. It is predicted that in the 25 years from 2016, the proportion of the British population that is aged 65 or older will increase by 8% (ONS, 2018). By 2041, people aged over 85 are predicted to make up 4% of this population (ONS, 2018): an increase of 1.6 million people since 2016. This phenomenon, referred to as "demographic ageing", is the result of people living longer and birth rates falling (ONS, 2018 p. 12). Consequently, often older people have fewer or no children or grandchildren to care for them (ONS, 2018). In addition, people are leading more dynamic lives, changing their physical location, job and even partners more frequently than previous generations did (Hyde and Higgs, 2016). This means that traditional family structures, in which older couples live near to their adult children and grandchildren, are becoming less common – despite the importance of the family in providing care and support to older relatives.

At the same time, as people get older they are more likely to be affected by disabling health conditions, such as cognitive or visual impairments, coronary disease, diabetes and muscular-skeletal conditions (Green et al., 2017; Kingston et al., 2017). Conditions are disabling when they restrict a person's ability to perform even basic ADLs, and long-term care is then required (World Health Organisation, 2003). Mobility, which can decrease with age, is crucial for performing ADLs and, in turn, being independent of support (Chappell and Cooke, 2010 p. 1). As more people need support, there is more demand for adult social care; at the same time, however, there is an

increasing shortfall of informal family carers. Many older people who continue to live at home are not having their social care needs met (NIHR School of Social Care Research [NIHR], 2017). This is because of the uncertain availability of support for meeting basic needs and barriers to accessing information on how to arrange care, amongst other factors. In many cases, this leads to social isolation and frustration (NIHR, 2017). In these circumstances, care homes may become suitable alternatives to living at home.

1.5 Research aims and questions

This thesis has the following overall aims:

1. To contribute to the debate on the rights of older people in long-term care by exploring multiple perspectives on the potential role of human rights in the context of care homes.
2. To build a mutual understanding of good practice in respecting care home residents' right to privacy.
3. To contribute to human rights research involving care home residents, care home managers, care workers, relatives of residents, and the CQC as the regulator of care services in England.

This research has three elements, which each contain research objectives and questions (see Table 1.2). The first element explores the CQC's perspective on the potential role of human rights in the context of care homes. The second emphasises perspectives on the topic from care home managers, workers, residents and relatives. During the data collection and analysis, the wider context of care homes was considered. The third element used the right to privacy as a case study in order to understand multiple perspectives on the practical implications of human rights in care homes.

Table 1.2 Overview of the research elements

Element	Objective	Research questions
Element 1: CQC research	To explore the CQC's perspective on the potential role for human rights in care homes through critically engaging with a range of CQC documents and experts.	What is the background to the CQC's human rights approach? What is the CQC's explanation of their human rights approach to regulation and inspection? What is the role and purpose of their human rights approach, according to it?
Element 2: Care home research	To explore perspectives on the potential role of human rights for people living, working in and visiting care homes.	How do people visiting, living and working in care homes understand the concept of human rights? What role do participants think human rights

		play for care homes? What role do participants think human rights *could* play for care homes?
Element 3: Right to privacy	To explore the practical implications of the human right to privacy in a care home context from multiple perspectives.	What is the evidence for good practice in protecting care home residents' right to privacy? What according to study participants is necessary to protect the right to privacy in a care home setting? What, according to CQC inspection reports and other relevant documents, is good and bad privacy practice in care homes?

1.6 Overview of the chapters

This thesis is organised in two parts. Part I (Chapters 1–6) introduces the thesis, provides contextual information, explains the research methodology and reviews the literature on human rights and care homes. Part II (Chapters 7–13) presents the findings of the study and includes the discussion chapters, sets out the limitations and recommendations, and concludes the thesis.

Chapter 2 sets out the three levels (international, regional and national) of human rights protection, and explains that governments are the main duty-bearers for human rights. It argues that a trickling-down process of transferring human rights obligations to non-state actors is taking place. This makes the discussion of human rights in care homes for older people relevant, even if they are run by independent providers. It discusses the international debate on older people's human rights as a further significant development that is relevant to this thesis. It also explains the national context for human rights research in England.

Chapter 3 summarises the marketised system of care homes in England, which is dominated by independent companies and characterised by high levels of regulation to ensure service quality. It provides information about the people in the care home community, especially those who live in, work in or visit care homes.

Chapter 4 turns to the human rights framework governing English care homes. It explains that care homes in England have three grades of human rights obligations by law and under the CQC regulations. It explains how the framework discriminates against certain parts of the care home population and links this with the traditional reliance on the government to protect human rights.

Chapter 5 explains the methodology and methods used in this study. It also describes the ethical considerations when conducting human rights research in care homes for older people.

Chapter 6 reviews the literature on human rights in care homes. It develops an initial typology of perspectives on the potential role of human rights in English care homes. This typology is extended in Chapter 10 on the basis of this study's findings.

Chapter 7 focuses on the CQC's human rights approach to regulating care homes. The first part of the chapter explores this approach from the perspective of organisational value. It complements Chapter 4 by analysing the extent to which the CQC's approach holds care service providers accountable for human rights. The second part of the chapter reports the CQC expert participants' perspectives on the potential role of human rights in care homes in England.

Chapters 8 and **9** report the findings from the perspectives of people living in, working in and visiting care homes.

Chapter 10 integrates the findings in Chapters 7 to 9 and discusses them in the context of the typology developed in Chapter 6 and the contextual information provided in Chapters 2–4. It argues that four types and several sub- perspectives emerged from the research, adding to the typology of Chapter 6.

Chapter 11 provides a short review of the literature on the concept of privacy and the right to privacy in care homes for older people. It then presents the findings on the practical meaning of the right to privacy in care homes. A right to privacy in care homes model is developed. This consists of six privacy topics and three key aspects of maintaining the right to privacy structured around the concept of "home".

Chapter 12 reflects on the right to privacy in care homes model by taking into consideration the typology of perspectives presented in Chapter 10. The model provides a practice-oriented basis from which to extend the discussion on each perspective.

Chapter 13 highlights some overarching observations on the study's findings and mentions the limitations of this research. It provides recommendations for people engaging with the topic of human rights in care homes for older people and for further research. It ends with an overall conclusion.

2 Human rights research in care homes for older people

This chapter introduces the wider context of human rights research in English care homes. Its purpose is two-fold. Firstly, it summarises the international, regional and national systems for protecting human rights and details some country-specific considerations around human rights that rationalise this research. This includes the social and political context, in which human rights are at times considered critically and perceived negatively. Secondly, this chapter sets out two key developments in the international system of human rights protection: a trickling-down process of transferring human rights obligations to non-state actors and a debate on older people's human rights. The chapter sets the scene for Chapter 4, in which the human rights framework governing English care homes is discussed.

2.1 Human rights on the international, regional and national level

2.1.1 The international human rights regime: content

The concept of human rights is not an invention of the 20th century. It has its roots in ancient natural and divine law, in political thinking (e.g. that of 17th century philosopher John Locke) and in early declarations of rights, including the Magna Carta of 1215 and the United States Bill of Rights 1783 (Nickel, 2007 p. 12).

However, the aftermath of the atrocities committed by Hitler's Germany during World War II spurred the development of the modern "international movement of human rights" (Nickel, 2007; Steiner et al., 2007). These rights were rooted in a body of international law and enforcement mechanisms: the "international human rights regime" (Steiner et al., 2007 p. 59). Human rights scholar James Nickel (2007 p. 7) summarised the purpose of the movement as follows: "to formulate and enforce international norms that will prevent governments from doing horrible things to their people and thereby promote international peace and security". The UN General Assembly was striving for "universal validity" of human rights as objects of international action and concern (Nickel, 2007 p. 14; Steiner et al., 2007 p. 59).

The UDHR 1948 was not legally binding; thus, in 1966 it was followed by two treaties: the International Covenant on Economic, Social and Cultural Rights (ICESCR) and the International Covenant on Civil and Political Rights (ICCPR). Together, these documents are referred to as the International Bill of Human Rights (henceforth, the Bill of Human Rights). Treaties are signed and then ratified by member states of the UN. By ratifying a treaty, a government agrees to respect and implement the rights it covers and to accept and respond to international criticism of its human rights records (Nickel, 2007 p. 15). The Bill of Human Rights was later complemented by other

treaties, which together make up the international human rights regime (Table 2.1). Enshrining human rights in law built the backbone for the international human rights movement; and the possibility of punitive action and international shaming drives protection of those rights (Steiner et al., 2007).

Table 2.1 The international human rights regime

Document	**Year adopted**
Universal Declaration of Human Rights (UDHR)	1948
Convention against Genocide	1948
International Covenant on Economic, Social and Cultural Rights (ICESCR)	1966
International Covenant on Civil and Political Rights (ICCPR)	1966
Convention on the Elimination of All Forms of Discrimination against Women (CEDAW)	1979
Convention against Torture and Other Cruel, Inhuman or Degrading Treatment and Punishment	1984
Convention on the Rights of the Child	1989
International Convention on the Protection of the Rights of All Migrant Workers and Members of their Families	1990
Convention on the Rights of Persons with Disabilities (UNCRPD)	2006
International Convention on the Rights of All Persons from Enforced Disappearance	2006

The rights and freedoms contained in the UDHR are commonly grouped into two categories: (1) economic, social and cultural rights; and (2) political and civil rights. Examples of the former are the right to work (Art. 23.1) and the right to education (Art. 26.1). Examples of the latter are the right to freedom of opinion and expression (Art. 19) and the right to life, liberty and security of the person (Art. 3).

There is political controversy about this categorisation, because economic, social and cultural rights have been considered as second class or not human rights at all (e.g. Cranston, 1964; Shue, 1980). However, the equal value of all rights was confirmed at the World Conference on Human Rights in Geneva in 1993, where it was proclaimed: “All human rights are universal, indivisible and interdependent and interrelated. The international community must treat human rights globally in a fair and equal manner, on the same footing, and with the same emphasis” (United Nations, 1993). The indivisibility, interdependence and inter-relatedness of human rights recognises that one human

right builds on another (Donnelly, 2003 p. 29). As Donnelly (2003 p. 28) stated: "A right to education may be as essential to life of dignity as freedom of speech or religion. [The economic and social] Rights to food and healthcare may be as essential for protecting life as the [political and civil] right to life". Thus, governments are responsible for protecting all human rights. The current categorisation of human rights is frequently used to refer to the content of the ICESCR (economic, social and cultural rights) and the ICCPR (political and civil rights).

2.1.1.a Human rights principles

Besides the rights and freedoms contained in the Bill of Human Rights, academics and practitioners frequently refer to "human rights principles" or "grounding values". These include dignity, equality, independence, autonomy, fairness and respect (e.g. Dworkin, 1981; Griffin, 2008; Waldron, 2015). Most of these principles are not *rights* in themselves. Rather, they are used to summarise or form a basis for philosophical reflections on human rights (Tasioulas, 2010). Nevertheless, some of them feature prominently in the Bill of Human Rights. In addition, Part II of this thesis reveals that they are prominent in perspectives on the potential role of human rights in care homes for older people. Therefore, it is worth reflecting on these principles here.

Dignity

Human dignity is widely accepted as the foundational concept of international human rights law (Donnelly, 2013 p. 28; Klug, 2015; Waldron, 2015). The preambles of the ICCPR and ICESCR proclaim that "the rights [within the respective Covenants] derive from the inherent dignity of the human person". However, the legal instruments do not define the meaning of dignity or how human rights can be derived from it. The principle of dignity has a long history in philosophy and political thought (Waldon, 2015 p. 121). Interpretations of dignity from a relativist constructivist perspective are not always directly related to human rights (Donnelly, 2013). Nevertheless, in international law, human rights are often considered instrumental for recognising and protecting dignity.

Equality

Equality features heavily in the Bill of Human Rights. Enshrining the right to be free from discrimination in Article 1 of the UDHR was a "quantum leap in terms of the scope attached to equality" (Klug, 2015 p. 42). The primary purpose of the CEDAW and the UNCRPD (see Table 2.1) is to enshrine equal rights for women and people with disabilities. The role of egalitarianism in international human rights law "is evident, first, in the great emphasis [human rights documents] place on equality before the law and protection against discrimination" (Nickel, 2007 p. 12).

Autonomy, independence and individualism

Autonomy, independence and individualism are frequently considered to be grounding human rights principles. Their roots stem from the works of philosophers, such as Emanuel Kant's conceptualisation of autonomy (Gregor, 1997), which is still pivotal in modern philosophical reflections on human rights. In Kant's school of thought, autonomy usually equates to self-determination; thus, we have autonomy when we can make choices and control our lives without interference from others. Because Kant's conceptualisation of autonomy links directly to human dignity, it has been transferred to debates on the philosophical foundations of human rights (Waldron, 2015). Independence as a core dimension of autonomy is a central value in liberal political theory and liberal individualism in particular (Nedelsky, 2011 p. 118). An individual who is independent is free from interference from others when making choices about their life. Feminist thinkers, however, have argued that such conceptions of autonomy fail to account for "the social and relations dimensions of humanness" (Nedelsky, 2011 p. 120). Therefore, alternative understandings of autonomy have at their core the recognition that the individual is determined by social relations (Nedelsky, 2011 p. 120).

Fairness and respect

Under the UDHR, governments must respect human rights. The right to a fair and public hearing is enshrined in Article 10. Especially in England, fairness and respect are communicated as grounding principles of human rights alongside the principles of equality, dignity and autonomy. Together, they are often referred to as the FREDA principles. The FREDA principles provide a more practice-oriented understanding of fairness and respect than the international human rights documents do, so government agencies (such as the NHS) have adopted them for the purpose of integrating human rights approaches into their work. A human rights approach can be understood as "putting the individual and her or his rights at the centre of processes" (Equality and Human Rights Commission, 2019a). In the FREDA principles, respect is defined as follows:

> [the] objective, unbiased consideration and regard for the rights, values, beliefs and property of other people. Respect applies to the person as well as their value systems and implies that these are fully considered before decisions which may overrule them are taken (Curtice and Exworthy, 2010 p. 152).

Fairness, on the other hand, is defined as "due consideration afforded to [a] person's opinion, giving them the opportunity to have that point of view expressed, listened to and weighed, alongside other factors relevant to the decision to be taken" (Curtice and Exworthy, 2010 pp. 151–152). The FREDA

principles are at the core of the CQC's human rights approach to regulating care services (see Chapter 7, section 7.3.1).

The reliance on grounding values when discussing human rights, and frequent references to these values as rights in themselves, has attracted criticism from human rights scholars. John Tasioulas (2010), a contemporary human rights philosopher, suggested that too much focus on abstract values as opposed to human rights themselves stands in the way of applying human rights in practice. According to Tasioulas (2010 p. 32):

> We should take more seriously… the fact that human rights are rights and not the prudential values that ground them. A proper appreciation of this fact opens up the way for us to embrace a pluralistic account of the grounds for human rights and to offer a more defensible interpretation of their universality and their role in practical conflict.

Nonetheless, in the social context of England, referring to grounding values often facilitates a debate about human rights amongst civil society actors. This is discussed in Chapter 2, section 2.3.3 and is apparent in this study's findings, as reported in Chapters 7, 8, 9 and 11.

2.1.1b Human rights rhetoric beyond the Bill of Human Rights

Human rights rhetoric is often used to further the causes and demands of political and social movements. In these cases, issues may be phrased in human rights terms even when they do not feature in the Bill of Human Rights. As Nickel wrote:

> It is easy to repackage a political movement's agenda in terms of rights, and the temptation to do so is sometimes strong. In the popular mind the idea of a right suggests a higher priority norm that you can do something about by litigating or protesting… If international recognition of the right is achieved, bodies such as the United Nations and the Council of Europe will include the right in declarations and treaties… (Nickel, 2007 p. 96).

Indeed, the list of human rights and freedoms contained in the Bill of Human Rights is still evolving. For example, there are developments towards a possible international convention that sets out the rights of older people, as discussed later in this chapter. The debate around which rights are human rights and the desirability of "human rights inflation" is still continuing 80 years after the UDHR was made. Many human rights scholars and practitioners oppose the inflation of human rights on the basis that this devalues all human rights (e.g. Fukuyama, 2001; Baxi, 2008).

2.1.2 Defining rights and duties under the international human rights regime

A right is usually understood as the basis for a justified demand (Shue, 1980; Nickel, 2007; Gearty, 2016). This implies that there are rightsholders (individuals or groups of individuals who are entitled to the right) and duty-bearers (individuals or organisations whose duty it is to comply with the demand) (Nickel, 2007 p. 9; Alston and Goodman, 2013). In a classical analysis of human rights, Henry Shue (1980) identified four duties that apply: (1) to respect the rights, which can be interpreted as not depriving the rightsholder of their rights; (2) to protect against deprivation, either through the duty-bearer or third parties; (3) to provide everything necessary to ensure that a rightsholder can enjoy their rights; and (4) to aid those who have been deprived of their rights; for example, through a judicial system and legal aid (Shue, 1980 pp. 52–60; Donnelly, 2013 p. 36).

In the case of human rights, all human beings are rightsholders. Human rights do not have to be bestowed on us; for example, through contractual relationships or citizenship. This differentiates human rights from other rights, such as civil rights or contractual rights. Consumer rights are not usually considered human rights either, although some authors suggest that there is a link between human rights and consumer protection (e.g. Jagielska and Jagielski, 2012; Benoehr, 2013).

The main addressees of human rights are governments (Nickel, 2007 p. 10, p. 38). This is enshrined in the Bill of Human Rights. The preamble of the UDHR, for example, says: “Member States have pledged themselves to achieve, in co-operation with the United Nations, the promotion of universal respect for and observance of human rights and fundamental freedoms”. Following Shue’s four-fold logic of rights protection, governments must respect, protect and provide for human rights, and they must make available a system of judicial redress to aid those whose human rights have been violated (Shue, 1980 pp. 52–53).

Under the requirement to respect and protect human rights, governments must ensure that their actions, and those of other social actors, do not deprive their citizens of their human rights. They must put in place adequate systems, through policies, laws and regulations, to protect citizens from human rights violations (Shue, 1980 p. 55). However, sometimes, depriving someone of their right is justified. These exceptions are usually included in human rights treaties. Examples are imprisonment – and, thus, deprivation of liberty – on the basis of a fair trial (Art. 9.3(4) ICCPR). A person’s rights may also be restricted when two or more people’s rights clash and compete. In that case, it is usually the role of the courts to judge which claim overrides the other (Shue, 1980 p. 55).

Effective courts and legal remedies are often considered to be essential for protecting human rights: “Rights are likely to be well guaranteed where right-holders can challenge deprivations of their rights through fair and impartial courts whose judgements are reliably implemented” (Donnelly,

2013 p. 36). However, from the social provision perspective (e.g. Donnelly 2013), the role of the courts is limited. Although they can help to guarantee human rights, they cannot do so without adequate social structures in place. Courts and legal remedies are thus the "tip of the iceberg" for effective human rights protection (Donnelly, 2013 p. 36). This makes this research especially relevant.

2.1.2a Human rights duties of non-state actors

Although governments have a special role in the international regime of human rights protection, non-state actors are increasingly considered human rights duty-bearers as well (Wettstein, 2015). Such developments do not challenge the primary role of governments under human rights law *per se.* However, a trickling-down process of transferring human rights duties to non-state actors is taking place. The central role of government is honoured, yet specific roles of other actors, such as private companies, are being enshrined in documents. In the academic literature (e.g. Clapham, 2006; Vandenhole, 2015; Murray, 2016; Lane, 2018), this process is referred to as the 'direct/indirect horizontal effect of human rights law' or the 'third party' effect of human rights (from the German word *Drittwirkung*) (e.g. Preedy, 2000). On the one hand, the state's human rights obligations to the individual are "vertical", which reflects the different levels that the government and individuals operate on (Lane, 2018 p. 5). On the other hand, the 'horizontal' effect describes the human rights duties of non-state actors to other non-state actors. In the context of the UK's HRA (see Section 2.3.2), Phillipson (1999 p. 824) defined the horizontal effect as "the impact on the legal relations between private juristic persons". This effect can be direct or indirect.

When there is a direct horizontal effect of human rights, non-state actors can be held directly responsible under international or national human rights law (Young, 2007). For example, a direct horizontal effect could apply to some care homes in England under Section 73 the Care Act 2014 (see Chapter 4, section 4.1). The literature on the direct horizontal effect extends to discussions around the United Nations Guiding Principles on Business and Human Rights (UNGPs). Some authors, such as Kanalan (2016), argue for a direct horizontal effect of human rights beyond legally binding documents, which they consider too restrictive an approach to human rights obligations. Kanalan (2016) proposes questioning the traditional conceptions of human rights and human rights obligations so that non-state actors' accountability is not limited to what is enshrined in the law.

When there is an indirect horizontal effect of human rights, non-state actors may not be directly liable by law. However, government bodies could be held responsible for human rights violations committed by non-state actors under their duty to protect. Phillipson (1999), for example, argued that under the HRA, British judges must apply human rights law in judgements involving non-state

actors. This equates to an indirect horizontal effect of human rights (Phillipson, 1999 p. 827). Although the literature on the horizontal effects of human rights is relevant to this research, this thesis does not contribute to that debate. Instead, it describes the human-rights-oriented legal and regulatory framework governing English care homes as "the trickling-down process of transferring human rights obligations to non-state actors".

Outside the literature on the horizontal effects of human rights, political and social scientists have created several process models that could be used in this thesis to frame and analyse the trickling-down process of transferring state obligations to non-state actors. For example, the five-phase spiral model of human rights change demonstrates the steps involved in diffusing international human rights norms (Risse et al., 1999 p. 5). This considers transnational and domestic advocacy networks and processes of "norm internalisation" in nation states. Another theoretical/conceptual lens is the human rights and social movement model (Stammers, 2009), which proposes that changes relating to human rights happen through "democracy-oriented activism" (Stammers, 2009 pp. 8–9). However, these theoretical frameworks are useful for analysing international and national processes relating to human rights, which is not the focus of this study. Rather, this thesis aims to use explanations of these processes to contextualise the findings on the potential role of human rights in care homes for older people. The following section considers the status of private companies and individuals in the international regime for protecting human rights.

2.1.2b Private companies and human rights

Globalisation and progressive marketisation have led to a rising influence of private companies over individuals' lives: "In the process of globalization, the power and reach of national governments has gotten increasingly constrained, while that of non-state actors, among them particularly large multinational companies, has dramatically increased" (Wettstein, 2015 p. 164). This is apparent in several cases of widespread human rights violations at the hands of private companies. An early example was the Bhopal disaster in 1984, in which around 600,000 people were exposed to toxic gases due to severe shortcomings of the company Union Carbide.

Responding to this rising influence of private companies, the UN adopted the Protect, Respect and Remedy framework in 2009 and the UN Guiding Principles on Business and Human Rights (UNGPs) in 2011. The framework and the UNGPs highlight a distinct (corporate) responsibility for business enterprises to respect human rights (UNGPs, Principle 11). Businesses must avoid infringing people's human rights, either directly or through their business relationships, and they must address adverse impacts if they happen (UNGPs, Principle 11, Commentary). They must also try to prevent and mitigate any adverse impacts on human rights that are directly linked to them through their business

relationships (UNGPs, Principle 11, Commentary). The framework and guidelines encompass all internationally recognised human rights and apply to all businesses (UNGPs, 2011, Principle 14). The corporate responsibility exists irrespective of whether a state is discharging its duty to protect under human rights law (UNGPs, Principle 11, Commentary).

Although the UNGPs are important because they acknowledge the duties of private corporations, they are legally non-binding (Bilchitz and Deva, 2015 p. 1; Rodriguez-Garavito, 2017). Nevertheless, the framework and the UNGPs have raised awareness of the potential impact of private companies on human rights (Nolan, 2015). Furthermore, corporations must now act in accordance with relevant national policies, laws and regulations and a widely recognised "social norm of a corporate responsibility to respect human rights" (Ruggie, 2013 p. 60). This is an important step towards a "direct horizontal effect of human rights" (Lane, 2018 p. 7). Despite this, the framework confirms that states have the primary *duty to protect* human rights against abuses by third parties, including businesses, by putting in place policies, legislation, regulation and enforcement mechanisms (UNGPs, Principle 1).

2.1.2c Individuals as duty-bearers of human rights

Human rights can also have implications for the conduct of individuals. The UDHR states: "every individual and every organ in society, keeping this Declaration constantly in mind, shall strive by teaching and education to promote respect for these rights and progressive measures national and international to secure their universal and effective recognition and observance" (UDHR, Preamble). Article 29 elaborates on this:

> Everyone has duties to the community in which alone the free and full development of his personality is possible. In the exercise of his rights and freedoms, everyone shall be subject only to such limitations as are determined by law solely for the purpose of securing due recognition and respect for the rights and freedoms of others... (Art. 29, UDHR).

Klug (2015 p. xiv) argued for an "ethic of universal human rights", where the main duty-bearers of human rights are governments but individuals have related moral duties. A debate referred to as "human rights in the private sphere" (e.g. Clapham, 1996; Thomas, 2015) considers the legal implications for individuals under human rights law. Although national legal frameworks can be understood to hold individuals indirectly accountable for human rights, there are some exceptions. The United Nations Convention on the Rights of the Child, for example, places direct responsibilities on parents but assigns governments a correlative duty to ensure that parents act on those

responsibilities (Klug, 2015 p. 48). As argued in Chapter 4, the trickling-down process of transferring human rights obligations to non-state actors is also taking place in the context of care homes for older people. This means that some care home providers can be held liable (under national human rights law and regulations) for human rights violations committed by individuals inside those care homes.

Given that the tradition has been to rely on state actors to protect human rights, academics have sought to explain why individuals are becoming duty-bearers. Nickel argued that human rights are addressed to all – governments and citizens – who share the responsibility for protecting those rights. He wrote:

> One approach to explaining how and why citizens share in the duties generated by human rights views the citizens of a country as having ultimate responsibility for the human rights duties of their government… They are required as voters, political agents and taxpayers to try to promote and support their government's compliance with its human rights duties (Nickel, 2007 p. 40).

Others, such as Morsink (1953), considered that humans are social beings who live in communities, with correlating rights and duties that are "grounded in the same communal soil" (Morsink, 1953 p. 244; Klug, 2015 p. 45). As mentioned in Chapter 1, human rights can be approached as a relational concept. That is, human rights in law and as a normative concept can unfold in relationships, including between private individuals.

Nevertheless, the primary addressee of human rights duties is still widely considered to be the government. As argued in Chapter 4, this also emerges from the current human rights framework that governs English care homes (Nickel, 2007 p. 38).

2.2 Regional human rights: the Council of Europe and the European Convention on Human Rights

2.2.1 The Council of Europe

The second level of human rights protection is characterised by a regional human rights system around the world. Western European nations founded the Council of Europe (CoE) in 1949 in response to the atrocities committed during World War II. The CoE is independent of the European Union (EU) and the European Council. One of its core purposes is to promote human rights across Europe, and it currently has 47 member states. In 1950, the CoE member states agreed to the ECHR, which contains similar civil and political rights to those in the ICESCR. The ECHR does not contain any

economic, social or cultural rights. Rather, these are enshrined in the European Social Charter of 1961.

The ECHR also established the European Court of Human Rights (ECtHR) in Strasbourg. Its primary purpose is to judicially enforce the ECHR. As of Spring 2019, individuals and organisations may file cases against CoE member states if they believe that any of the ECHR's articles have been violated and they have exhausted all the national judicial avenues. If the court finds that human rights contained in the ECHR have been violated, the violating member state must usually remedy the situation and change its laws and regulations to avoid future breaches (Rainey et al., 2017). Between 1959 and 2017, the ECtHR handed down 20,637 judgements, including some where countries were not found to have violated human rights. Of all those judgments, 545 were directed at the UK: 341 of them for violating at least one right contained in the ECHR. The three rights most commonly violated by the UK in these judgements were the right to a fair trial (93 violations), the right to liberty and security of the person (69) and the right to a family and private life (68) (see Table 2.2).

Table 2.2 ECtHR judgements between 1959 and 2017

Judgement	**Number**
SUM of judgements to all member states:	20,637
SUM of judgements directed at UK:	545
SUM of judgements directed at UK for violation of at least one Convention right:	341
Most frequently violated articles by UK government	
1: Right to fair trial:	93
2: Right to liberty and security of the person:	69
3: Right to family and private life:	68

In theory, people in English care homes (or their relatives) can address the ECtHR if they believe that the British government has violated their human rights. Indeed, around 12% of the ECtHR rulings between 2000 and 2010 concerned the rights of older people (Spanier et al., 2013 p. 407). Furthermore, a case in 2011, *Heinisch v Germany*, involved a care worker who claimed that her rights had been violated when she was dismissed from a German care home following whistle-blowing.

In practice, however, it may be difficult for care home residents and their relatives to access the ECtHR. It has been criticised for being ineffective due to a large backlog of cases. In November 2018, 57,500 cases were pending allocation to one of the judicial chambers of the court, and 40,650 new

cases were filed in 2018 alone (Council of Europe, 2019). As discussed in Chapter 10, the question of access to justice mechanisms arises for any legal role of human rights in the context of care homes.

2.2.2 The EU

EU member states have been subject to the Charter of Fundamental Rights of the European Union since 2009, which protects the rights and freedoms of EU citizens. The European Court of Justice interprets the charter's rights and freedoms. EU member states that have ratified the ECHR are also subject to the ECtHR. When Britain leaves the EU, the charter will no longer apply but the ECHR will.

2.3 Human rights protection at the national level: England

The third level of human rights protection is a national one. The UK government has ratified all treaties in the Bill of Human Rights and is a member state of the CoE. It has also endorsed the UNGPs (Foreign and Commonwealth Office, 2016). Thus, the UK government is bound by international human rights and regional law and is subject to the ECtHR. In England, human rights increasingly has a role outside the courts; it is often the basis for public action, an element of overarching regulatory frameworks, or part of minimum standards in public policy (Klug,2015; Vizard, 2016). In this context, human rights are infiltrating the legal and regulatory framework governing English care homes (see Chapter 4).

At the same time, human rights scholars have observed that "the meaning of the phrase human rights is contested territory in modern Britain" (Klug, 2015 p. 13). The following sections describe the historical, legal and regulatory, and social contexts of human rights in England, where this research took place.

2.3.1 Historical background: human rights in British politics

Human rights have a long history in British politics (Klug, 2015; Gearty, 2016). The Magna Carta of 1215, which was drafted by the Archbishop of Canterbury and signed by King John, listed landowners' rights, and the 1689 Bill of Rights gave citizens other rights and freedoms (Klug, 2015). Winston Churchill, the prime minister of Britain during and after World War II, along with other British politicians, played a significant role in developing the international human rights regime (Gearty, 2016). Britain was involved in drafting the UDHR, with Labour politician Charles Dukes a member of the drafting committee. Churchill, in a speech in September 1946, raised the idea of building the CoE and the ECHR: "In the centre of our movement [referring to the creation of the Council of Europe] stands the idea of a Charter of Human Rights, guarded by freedom and sustained by law" (Churchill Society, 2019a, 2019b). He was the first to sign the ECHR in 1950. Later, in the

1990s, the government adopted some important Acts of law, which are discussed in the following section.

2.3.2 Mechanisms for protecting human rights in England

2.3.2a The Human Rights Act 1998 (HRA)

The introduction of the HRA in 1998 by the Labour government was a major milestone in British human rights history (Klug, 2012). The HRA directly translates the ECHR into British law. This has three consequences: firstly, any individual can bring a human rights claim to the British courts against British public authorities. Although the ECHR is directly applicable in British courts (because of the HRA), people may take their claim to the ECtHR after they have exhausted all judicial avenues in Britain. Secondly, Section 6(1) of the HRA requires all public authorities to act in line with Convention rights (i.e. the rights and freedoms contained in the ECHR). Thirdly, under Section 3 of the HRA, all UK laws must be interpreted in line with the Convention rights as far as possible, and no Acts of Parliament must violate those rights and freedoms. Section 4 gives British courts the power to issue "declarations of incompatibility" for any new Acts of Parliament that are thought to breach the HRA. However, although such declarations can highlight inconsistencies between Acts of Parliament and the Convention rights, they have no legal effect. The Joint Committee on Human Rights, which has 12 members appointed from the House of Commons and the House of Lords in the Westminster Parliament, scrutinises government bills for compatibility with human rights and government responses to court judgements, including those of the ECtHR (Houses of Parliaments, 2019).

The Equality Act 2010

Equality is a fundamental human right under the Bill of Human Rights, and Article 7 of the UDHR requires governments to outlaw discrimination. In 2010, the British government introduced the Equality Act to "harmonize equality legislation and to strengthen the law to support progress on equality" (Equality and Human Rights Commission, 2017). The Equality Act merged 116 pieces of legislation on equality issues in Britain (for example, the Sex Discrimination Act 1975, the Race Relations Act 1976 and the Disability Discrimination Act 1995). The Act primarily addresses employers and employees; thus, it protects people in Britain from discrimination at work and in wider society based on "protected characteristics" (Government Equalities Office, 2015). Case law under the Equality Act is often heard at an employment tribunal, but individuals may also be prosecuted under criminal law for acts of violence, harassment or verbal abuse on the grounds of protected characteristics.

Protected characteristics include race, religious background, sexual orientation, gender reassignment, pregnancy status and disability. The Equality Act also largely outlawed discriminatory behaviour based on age (age discrimination) apart from when there is an objective justification (Equality Act 2010, Chapter 1). A recent government study (House of Commons, 2018) suggested that age discrimination persists in the workplace in spite of the Equality Act: there is an imbalance between the number of litigation cases and the amount of discrimination in reality (House of Commons, 2018 p. 12). Ageism is discussed in more depth in Section 2.4.1 of this Chapter.

Other laws

Theoretically, all laws in Britain must be compatible with the rights and freedoms in the ECHR. The Care Act 2014 and the Mental Capacity Act 2005 (MCA) in particular are relevant for human rights research in the context of care homes. The Care Act is the primary legal basis for social care and support provided through local authorities in England (see Chapter 3 .1.1) for a definition of local authorities). By placing a duty on public authorities to promote individuals' well-being, the Act refers to the underlying principles of human rights, such as dignity and control. It strengthens the right to be protected from abuse and neglect, which relates directly to the right not to be subjected to inhumane or degrading treatment (Art. 3, ECHR). Under the Care Act, local authorities must also put in place "adult safeguarding boards". These boards review the circumstances in which people who need care and support have been harmed, in order to learn from any shortcomings identified (Care Act 2014, s.44). The relevance of the Care Act to this study is discussed in more detail in Chapter 4, section 4.1.

The MCA came into force in 2007. The Act provides a legal framework in England and Wales to protect people from being arbitrarily deprived of their capacity to make decisions about their everyday lives and to protect adults who lack that capacity. Approximately 70% of care home residents are living with dementia (Alzheimer's Society, 2016), which makes this Act important for care homes and their employees, residents and visitors. Dementia is a neuro-degenerative brain disorder, which progressively leads to loss of memory and other brain functions. Medication can slow down its progress, but there is no cure. Dementia can begin at any age, but people aged 65 or older are the most widely affected group. It is therefore often considered a condition of old age (Alzheimer's Society, 2019). Advanced dementia may rob people of their capacity to make decisions, and these people are protected under the MCA.

Section 1 of the MCA spells out the guiding principles. These are underpinned by a "right to personal autonomy": the right to maintain control over one's own life (Murrell and McCalla, 2015; Jones and Piffaretti, 2018 p. 17). They include the presumption of capacity, the right to supported decision-

making, the right to make unwise decisions, and best-interest decision-making on behalf of people who lack capacity.

Accordingly, a person must be assumed to have the capacity to make decisions unless a test (set out in the Act's Code of Practice) shows that the person lacks that capacity. Before a person is considered to lack capacity, they must also have received practical help to make decisions (the "right to support with decision making") (MCA 2005, Part.1, Part.2, MCA Code of Practice 2007, Chapter 4). In theory, anyone caring for or supporting a person can assess their capacity (CQC, 2011). This means that care homes and hospitals do not have to rely on psychiatric professionals for such an assessment. However, some studies have suggested that capacity assessments are not routinely undertaken in care settings or that the outcomes can be arbitrary depending on the opinion of the assessor (e.g. Bartlett, 2015). Other academic research, some of which was conducted in hospital settings, found that care staff lack training and highlighted multiple perceived challenges surrounding mental capacity assessments (Manthorpe et al., 2011; Harding and Taşcıoğlu, 2017; Jayes et al., 2017). A study on the Everyday Decisions Project, which supports decision-making for people with intellectual disabilities, found that in general care professionals had a good awareness of the MCA, including the right to supported decision-making (Harding and Taşcıoğlu, 2017 p. 15). However, the study also suggested that with increasing levels of decisional complexity, for example around medical or legal decisions, care professionals struggled to support people with disabilities in decision-making (Harding and Taşcıoğlu, 2017 p. 20).

Another principle of the MCA (P.3) is that a person must not be treated as lacking capacity due to perceptions that they are making an "unwise" decision. The Mental Capacity Act Manual (2018) defines an unwise decision as "an irrational, capricious, spiteful or eccentric decision which, viewed objectively, is not in that person's best interest" (Jones and Piffaretti, 2018 p. 17). Care home residents, therefore, have the right to make unwise decisions about their everyday life without care staff treating them as lacking capacity. However, repeated unwise decisions or decisions that are out of character may "raise concerns" (MCA Code of Practice, 2007 p. 25). In this case, further investigations should be carried out, but in the meantime the person should still be presumed to have capacity (MCA Code of Practice, 2007 p. 25). In practice, however, care home staff must to balance these rights with their duty of care (Murrell and McCalla, 2015; Taylor, 2016). Care staff may determine that an individual lacks capacity if they make an "unwise decision", especially if that decision is presumed to risk the health and safety of the individual or other residents (Murrell and McCalla, 2015). This is supported by some of the findings of this study.

Furthermore, anything done or decided for someone who lacks capacity must be in the person's best interests (MCA, P.4). Section 4 of the MCA spells out the steps that must be followed when making a decision on behalf of someone who lacks capacity. For example, anyone making best-interest decisions must take into account the person's character, including their values and wishes (s.4(6)(a-b)), and consider their "relational life", such as people who are caring for them or "interested in their welfare" (s.4(7)(a-d)) (Harding, 2017a p. 30). Anyone making a decision on someone else's behalf must consider all the alternatives and choose the least restrictive one, balancing the rights of and risks to the person.

The MCA also makes provisions for Deprivation of Liberty Safeguards (DoLS) in accordance with Article 5 of the ECHR, "the right to liberty and security". DoLS are care or treatment regimes for people who lack capacity to consent. For their own safety and best interests, these regimes deprive them of their liberty. To be able to deprive someone of their liberty in a care home, an authorisation from the local authority or a court order is required unless the deprivation of liberty is necessary to provide urgent life-sustaining treatment or perform "vital acts", which is any act an individual feels necessary to prevent a serious deterioration of another person's condition (MCA, s.4A, s.4B). Authorisations are currently based on an assessment by two qualified professionals. They are valid for up to 12 months, after which a new authorisation is needed.

The MCA does not define "deprivation of liberty". A supreme court judgement of May 2014 (*P v Cheshire West & Cheshire Council 2014* [UKSC] 19) made reference to an "acid test" to determine whether a care home resident is being deprived of their liberty. The test is whether the person "was under continuous supervision and control and was not free to leave" (Jones and Piffaretti, 2018 p. 321). However, some forms of physical restraint or restrictions that are in the person's best interests may not amount to deprivation of liberty. Each year, the government publishes data on the application of DoLS under the MCA 2005. In 2017/2018, 227,400 applications were filed, 34% of which came from residential care homes. Around 85% of all cases concerned people aged 75 or older. Of the 181,785 applications that were filed and completed, around 60% were granted (Health and Social Care Information Centre, 2018).

The DoLS system was introduced in 2007, following the ECtHR's decision about a man with autism who had been deprived of his liberty in an institutional setting (*HL v United Kingdom* (2004) 40 EHRR 761, the "Bournewood case"). However, the system has been widely criticised for being too complex, too costly and generally unfit for purpose (e.g. Harding, 2019). This has led to a legislative review, and DoLS will soon be replaced by Liberty Protection Safeguards, as set out in the Mental Capacity Act (Amendment) Act 2019. This Act will come into force in 2020 or afterwards.

Although the MCA 2005 is important for any human rights and care home researcher, it is not central to this thesis, because the focus is on the human rights of care home residents who do have capacity to make decisions (see Chapter 5). However, the findings chapters reveal that many of the study's participants, especially care home staff, frequently referred to the MCA and its provisions. This highlighted the significance of the MCA in care homes and in some of the related dilemmas.

For the purposes of this research, data protection legislation as part of the right to privacy is also significant. In 2018, the Data Protection Act was reformed to bring previous legislation into line with the EU General Data Protection Regulation (GDPR). This introduces new rules on the control and treatment of personal data, and anyone holding or working with such data could receive large fines for breaking these rules. The right to privacy and data protection in the context of care homes is discussed in Chapters 11 and 12.

Human rights protection beyond the courts

Other organisations in England work to protect and promote human rights and are mentioned frequently in this thesis. The Equality and Human Rights Commission is a statutory non-departmental public body that is responsible for enforcing the Equality Act by "eliminating discrimination" and promoting, protecting and raising awareness of human rights. It was established under the Equality Act 2006 (a predecessor of the Equality Act 2010) and has several regulatory powers. For example, it can launch enquiries to "find out more about human rights and equality in a particular sector" (Equality and Human Rights Commission, 2019b). Furthermore, it can offer legal assistance to victims of discrimination and intervene in court cases related to human rights and equality. The Commission has published reports on human rights and equality, some of which are mentioned in this thesis. The Joint Committee on Human Rights may also conduct thematic inquiries into human rights matters.

Other relevant organisations include grassroots groups and charities, such as the British Institute of Human Rights and Liberty. Their work on older people's human rights and in care homes is mentioned at several points in this thesis.

2.3.3 The future of the HRA and public perceptions of human rights in England

Despite the long history of human rights in Britain, there is political debate about replacing the HRA with a British Bill of Human Rights or discarding it altogether (Douglas-Scott, 2015; Gearty, 2016 p. 2). Gearty (2016 p. 2) argued that ever since repealing the HRA became part of the government manifesto in 2015, it has been "sentenced to death". Due to uncertainties around Brexit, which began with a referendum majority vote (51.9%) on 23 June 2016 for Britain to leave the EU, the

future of the HRA will remain undecided for some time. However, Britain is bound by international human rights irrespective of Brexit, its membership of the CoE or the existence of the HRA.

Public opinion has frequently been cited as a driving force for discarding or replacing the HRA. The HRA is often perceived as a tool that aids "undeserving" individuals: a view that has been fuelled by unfavourable media reporting on human rights (Klug, 2015; Counterpoint, 2016; Gearty, 2016). According to Gearty, "Received opinion has become so familiar with the idea of the Human Rights Act as the protector of villains that the perception has become normalized within our culture, assertion becoming truth in the absence of speedy refutation" (2016 p. 113).

In a recent study, the Equality and Human Rights Commission (2018) estimated that 10% of British people are "entrenched opponents" of human rights and are "intolerant of equal rights for minority groups" (Equality and Human Rights Commission, 2018a p. 4). Another study found evidence of "equality hypocrisy" in British society, in which some minority groups – particularly women, people with disabilities and people aged 70 and older – were considered *more* deserving and in need of human rights protection than others (Abrams et al., 2015a). Intolerance of equal rights was extended to people with diverse religious backgrounds: 22% of respondents felt that human rights had "gone too far" for people in the Muslim community (Abrams et al., 2015a).

According to the Equality and Human Rights Commission (2018), 45% of the British public are "disengaged neutrals", who are rather pessimistic and uninformed about human rights. Education in human rights may be one way to transform these attitudes, including in care settings (Equality and Human Rights Commission, 2018 p. 4; Kinderman et al., 2018). On the other hand, the Equality and Human Rights Commission estimated that 21% of British people are "enthusiastic advocates", who are optimistic and "empowered defenders of human rights" (2018a p. 4). This implies that negative perceptions are not as widespread as some have proposed.

Indeed, there is much support across the English population for values that underpin human rights, such as dignity, respect, fair treatment, privacy, and non-discrimination (Equality and Human Rights Commission, 2009; Equality and Diversity Forum, 2012; Counterpoint, 2016). To build public support for human rights, the Equality and Diversity forum (2012) has recommended "appeal[ing] to people's intrinsic values" rather than talking about the concept in terms of human rights directly. Reinforcing the basic value of equality helps to transform attitudes and make being unprejudiced a desirable personality trait (Abrams et al., 2015a).

The Equality and Human Rights Commission's study is part of a body of literature (e.g. Chors et al., 2007; Stenner, 2011; Hackett et al., 2015; McFarland, 2015) that seeks to capture human rights

attitudes, behaviour and their determinants in societies and groups. This work is often located in the field of political-psychology. Its common aim is to "encourage human rights commitment" (Twose and Cohrs, 2015 p. 6); for example, through education and raising "social consciousness" (Crowson, 2004; Cohrs et al., 2007 p. 251). Some of these contributions consider human rights attitudes and behaviour in a "dynamic relation" (Cohrs et al., 2007 p. 445) to basic human values. One theory on this proposes that there are ten types of motivational values, which are shared by societies across the world (Schwartz, 2012). Cohrs and colleagues (2007 p. 446) suggested that two of these values – universalism and benevolence – and their relative importance in a society can be linked to the level of human rights commitment.

This thesis recognises the multitude of attitudes to human rights that may be present in English society. Indeed, this recognition is even a rationalising factor in this study, as it seeks to capture multiple perspectives. However, this thesis does not aim to contribute to the academic literature on human rights and psychology, or to capture the attitudes of people in care homes to human rights as such. Rather, its focus is on the potential role of human rights in care homes from the perspectives of people with experience of working in, living in, visiting and regulating them. Although the discussion (Chapter 10) highlights a few more points that could be analysed by tapping into the literature around psychology, values and human rights, this is beyond the scope of this thesis.

2.4 The debate on older people's human rights

Except for the Convention on the Rights of the Child, international human rights law applies to people of all ages, including older people. However, there is ongoing international and regional debate about recognising older people's human rights in an international convention (the ICROP). Alongside the trickling-down process of transferring human rights obligations, this significant international development underlies this research.

The debate does not aim to create new human rights for older people (McHale, 2012; Poffé, 2017). Rather, it is about "the application of existing norms to the peculiar circumstances of older people", as the CEDAW does for women and the CRPD does for people with disabilities (Herro, 2017). As the topic of long-term care provision features prominently, this debate is directly relevant to this thesis (Rees and Meenan, 2016; European Network of National Human Rights Institutions, 2017; Herro, 2017).

This section begins by introducing the debate on a possible ICROP. It discusses ageism and concepts of active ageing, which at times drive this debate. Furthermore, older people's rights are often linked to the disability rights movement (e.g. Shakespeare, 2014; Cahill, 2017; Shakespeare et al.,

2019) and the UNCRPD. Together, these developments reflect a paradigm shift in disability and ageing discourse, in which older people – with or without disabilities – are active holders of human rights rather than "objects of charity" (Cahill, 2017 p. 51). This also concerns older people living in care homes, whose human rights must be continuously protected (Kelly and Innes, 2013). Therefore, this section discusses the relationship between disability rights and older people's rights. It also describes the role of care homes in the debate on older people's human rights. The literature on human rights in the context of older people in care homes is discussed in Chapter 4 and Chapter 6.

2.4.1 Towards an International Convention on the Rights of Older Persons

The Bill of Human Rights does not currently include a treaty on the rights of older people, and neither the UDHR nor the ECHR specify old age as a ground for discrimination (Tang and Lee, 2006). The only international treaty that refers to older people is the Convention on the Rights of Migrant Workers (De Pauw et al., 2018 p. 181). The Bill has been criticised as perpetuating the invisibility of older people in society, and with it many age-related injustices (Chung, 2009). Furthermore, it fails to account for the multi-dimensionality and intersectionality of the many problems and injustices faced by older people and issues of gender, race, religious background, sexual orientation and other personal characteristics (e.g. Chung, 2009; Westwood, 2016; Herro, 2017 p. 97; Kesby, 2017 p. 386).

On the international and regional levels, there is a growing recognition of the problems faced by older people that could be framed in terms of human rights violations. This process is sometimes referred to as "the human rights approach to ageing" (Kesby, 2017). Philip Alston, a human rights scholar, has argued that taking a human rights approach to a debate can be transformative, "making a general claim for charity, a general demand upon society's resources, into that of a priority issue" (Alston, 1987 p. 178). Therefore, a human rights approach to ageing could have two effects. Firstly, it could highlight that older people are entitled rightsholders, with governments and other actors as duty-bearers. Secondly, it could prioritise age-specific human rights topics, such as ageism, at the national level of human rights protection.

In 2010 the UN established an open-ended working group to strengthen the protection of older people's human rights (the OEWGA) with the view to drafting and adopting an ICROP. Although the UN has been adopting strategies for protecting older people's rights since the 1980s, none of them are legally binding. They include the UN Principles for Older Persons 1991 and the Madrid Political Declaration and the Madrid International Plan of Action on Ageing, both adopted in 2002. Setting up the working group is widely considered to be the biggest step towards serious international engagement with the rights of older people (Herro, 2017). The UK government is a member of the working group, but it has not taken a clear stance on whether it supports a new convention.

On the regional level, the CoE adopted a "Recommendation on the promotion of human rights of older persons" in 2014 that aims "to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by older persons, and to promote respect for their inherent dignity" (Council of Europe, 2014, Section 1). Another important milestone was the appointment of Rosa Kornfeld-Matte as the UN Independent Expert on the enjoyment of all human rights by older persons. Part of the role's large mandate is to "report on developments, challenges and protection gaps in the realization of the rights of older persons" around the world (United Nations, 2018).

Kesby (2017) looked at prominent narratives of ageing in public policy studies and critical gerontology to identify the pertinent, inter-related themes that drive this international debate around older people's human rights – and, thus, a human rights approach to ageing. The starting point is the recognition of older people as equal rightsholders. Accordingly, the first theme driving the debate is the perceived need to respond to the phenomenon of demographic ageing. The second theme is the engagement with ageism and the related "social recognition justice gap" faced by older people worldwide. The third theme focuses on theories of active ageing (Kesby, 2017). These themes engage with conceptual issues and theoretical reflections around older age, which are important for a study on older people's human rights. The concept of demographic ageing and some of the perceived challenges were introduced in Chapter 1, so they are not discussed again here.

2.4.1.1 Background to the debate on human rights and older people: ageism

Widespread ageism in societies is constantly identified as the root cause of many injustices that older people face (Herro, 2017). It is identified in public policy documents at the international, regional and national level, and in human rights advocacy work. Ageism is a human rights violation under Article 1 of the UDHR and Article 14 of the ECHR, even though age is not explicitly mentioned as a discriminatory characteristic. The growing awareness of the existence and potentially detrimental effects of ageism is leading to more recognition of the need to highlight older people in the human rights regime (Mégret, 2011).

Israel Doron, Head of The Center for Research and Study of Aging at the University of Haifa, has defined ageism as "the social and cultural construction of old age" (Doron, 2018). Definitions of ageism as a concept are often multidimensional, aiming to grasp all types, levels and perpetrators of ageist practices (e.g. Butler, 1969; Iversen et al., 2009). A relatively recent conceptualisation of ageism is as follows:

> …negative or positive stereotypes, prejudice/or discrimination against (or the advantage of) older people on the basis of their chronological age or on the basis of a perception of them being "old" or "elderly". Ageism can be implicit or explicit and can be expressed on a micro-, meso- or macro level (Iversen et al., 2009 p. 15).

In this conceptualisation, ageism has several dimensions and components. These include the three classical components, which were first defined by Butler (1969): cognitive stereotypes, affective prejudice or behavioural discrimination; positive or negative ageism; explicit or implicit ageism and the various levels on which ageism can take place (Buttigieg et al., 2018 p. 500). Furthermore, ageism can be self-directed. "Self-ageism" is when individuals hold stereotypical opinions about themselves or other people of their age (Bodner et al., 2015; São José et al., 2019). Thus, ageism can take many forms and appear in all spheres of daily life (Buttigieg et al., 2018).

Ageism is widespread in English society. Examples of negative ageist stereotyping include common beliefs that older people lack creativity, are unable to learn new skills, and are asexual, frail, dependent and socially isolated (Swift et al., 2013; Swift et al., 2017). Reported examples of positive ageism include stereotyping older people as wise, generous, friendly, moral, experienced, loyal and reliable (Swift et al., 2013). Recently, the Royal Society of Public Health (RSPH) (2018) suggested that ageism is not only the most commonly reported form of discrimination in England but also perceived as the most widely accepted, often left unchallenged even if it is explicit. It states: "Although few people would think of themselves as 'ageist' socially engrained ageist attitudes and behaviours are often openly expressed and displayed within mainstream culture without challenge. It has been argued that taboos around the open expression of ageist stereotypes, although real, are far weaker than in other areas" (RSPH, 2018 p. 7).

A review of the academic literature on ageism in long-term care settings, including care homes, identified studies that aimed to capture the existence of the problem in these contexts and concluded: "The literature on ageism in long-term care … presents a … balanced division of interests between [Butler's] three components. Negative stereotypes about conditions and abilities of older individuals … and about old age in general, as well as negative reactions and prejudice towards older people are well mapped in the empirical literature" (Buttigieg et al., 2018 p. 502). The consequences of ageism in long-term care are diverse, ranging from discriminatory language to poor-quality care or the segregation of residents (São José et al., 2017; Buttigieg et al., 2018 p. 502). Ageism in care settings may also be self-directed (Ayalon, 2015) or held from resident to resident (Roth et al., 2012).

The consequences of ageism can be devastating for victims. A broad body of literature links ageism – often combined with other types of discrimination – to human rights violations that perpetuate a social recognition justice gap. These include violence and abuse of older people, lack of access to justice, and the violation of liberty rights. They are justified in society by the systematic downgrading of older people. On the individual level, evidence suggests that ageism can harm mental and physical well-being and reduce life expectancy (Swift et al., 2017; RSPH, 2018). The embodiment of ageist attitudes in stereotypes can influence individuals' emotions, plans and behaviours in a self-perpetuating cycle (Levy, 2009; Swift el al., 2017; RSPH, 2018).

Several authors have suggested that in addition to promoting equal rights for older people, a new international legal instrument focusing on older people could emphasise the obligation of nations to tackle ageism in society. It is necessary, therefore, to account for the many aspects and forms of ageism that people encounter in life (De Pauw et al., 2018 p. 189). Indeed, the findings of this study suggest that ageist attitudes influenced some participants' perspectives on the potential role of human rights in care homes. Meanwhile, other participants thought of human rights as a tool for tackling ageism in these settings. This is discussed in Chapter 10.

2.4.1.2 Active ageing

Active ageing is the second theme in Kesby's analysis (Kesby, 2017 p. 387). This concept is seen as a counterweight to ageist perceptions and the challenges of demographic ageing, because it redefines older age as a period of active and productive participation in society (Kesby, 2017 p. 379). Mikolajczyk defined the ideal relationship between active ageing and the instruments combatting ageism (including human rights instruments) as one of mutual recognition and inter-relatedness: "The existence of instruments, including legal ones, intended to prevent age discrimination, fight stereotypes, combat prejudice against older persons, and promote intergenerational solidarity are sine qua non conditions for active ageing" (Mikolajczyk, 2018 p. 76).

Active ageing stems from the concepts of "successful ageing" and "productive ageing", which were developed in the United States in the 1960s and 1970s (Kesby, 2017 p. 378; Doron, 2018 p. 34). It has been influencing international and regional social policy since the World Health Organization published a report on active ageing in 2002 (Doron, 2018 p. 34). That report includes the following definition: "Active ageing is the process of optimizing opportunities for health, participation and security in order to enhance quality of life as people age" (World Health Organization, 2002 p. 12; Kesby, 2017 p. 379). Furthermore, some components of active ageing underlie the 1991 UN Principles of Older People and the Madrid Plan of Action, including the principle of independence through access to the labour market and the principle of full participation in society (Mikolajczyk,

2018 p. 74). In addition, active ageing is being aligned with human rights in current debates on the ICROP, thereby empowering older people "to become active, responsible, independent citizens" (Kesby 2017 p. 387). Some academics also embrace an active ageing approach in care homes (see Chapter 6). This reflects the theme in the international arena.

However, the concept of active ageing has attracted criticism. Some have argued that it fails to account for the disparity of circumstances and the inequality that exists amongst older people (Holstein and Minkler, 2003; Doron, 2018 p. 34). Furthermore, by placing the burden of "successful" ageing on "empowered" older people, the concept may encourage potentially harmful economic and social policies that do not support older people in their particular realities (Taghizadeh-Larsson and Jönson, 2018). With regard to older people's human rights, Kesby (2017 p. 387) warned that an active ageing approach is useful only to "foster inclusion and participation of older people into society"; if the approach is used for other purposes, it may reflect or even perpetuate the pitfalls of active ageing as a concept. In the context of care homes, where most older residents need care and support, the criticisms of active ageing in relation to human rights may be especially relevant. Here, the "ethics of care" debate on human rights (see Chapter 1) can challenge the liberal perceptions of human rights that underlie conceptions of active ageing. The debate can propose instead a relational approach that acknowledges the centrality of care and relationships for older people.

2.4.1.3 The ICROP: critical voices

Despite the international and regional developments in older people's human rights, some critics do not support a new ICROP (Poffé, 2015 p. 599). Posner (2014) has questioned the ability of human rights in general to bring about meaningful change. With regard to the ICROP in particular, some have argued that adopting a separate convention could perpetuate, rather than tackle, stigmas around older people in society. This illustrates that human rights as a concept that aims to achieve a certain outcome is contested. Therefore, it is acutely important to study this subject in specific contexts, such as care homes, to explore the realities of particular groups of older people.

2.4.2 Older age and the UN Convention on the Rights of People with Disabilities

The UNCRPD is relevant for older people in general and for those in long-term care in particular (Cahill, 2017). People are more likely to experience disability as they get older, and care home residents in England often have one or more disabling conditions. Yet, the debate on disability rights is distinct from the debate on older people's rights. Contributors to both debates disagree on whether extending disability rights to older people in general would be adequate, as not all older people are also disabled. However, before discussing this in detail it is important to understand the UNCRPD model of disability.

The range of definitions and models of disability highlights that the concept is "complex, dynamic, multidimensional, contested and evolving" (Mitra, 2006; WHO and WorldBank, 2011 p. 3). The UNCRPD definition, which is referred to as the "human rights model of disability" (Al Ju'beh, 2015; Rohwerder, 2015; Degener, 2016), is as follows: "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (UNCRPD, 2006 p. 4).

The UNCRPD is the product of a long-term international disability rights movement dating back to the 1970s. Adopting the UNCRPD was important for challenging the medical models of disability, in which disabilities are viewed in terms of physical health rather than social constructs. Proponents of the social model of disability believe that these constructs create unnecessary barriers for people with disabilities in society (Degener, 2016). However, the human rights model of disability differs substantially from the social model in three respects (Degener, 2016). Firstly, the human rights model can shape countries' disability policies on the basis of human dignity, whereas the social model merely proposes a perspective on disability. Secondly, the social model of disability focuses on disability-related discrimination, whereas the human rights model covers non-discrimination and all rights set out in the Bill of Human Rights. Thirdly, the human rights model recognises impairment as a matter of human variation and acknowledges the consequences, such as pain, dependency on others and early death. Public policies based on this model should therefore account for such variation (Degener, 2016, pp. 3–6).

The disability rights movement did not focus on concerns about disability in older age (Gilliard et al., 2005; Jönson and Taghizadeh-Larsson, 2009; Cahill, 2017). However, an increasing number of academic contributions are considering the UNCRPD from the perspective of older people and disability. In this literature on older people's human rights, models of ageing are important in identifying how useful it may be to extend the UNCRPD to cover older age. The older people's rights movement – and its core purpose of tackling ageism internationally – is supported by models of active ageing that challenge associations of older age with frailty, illness and impairment (Taghizadeh-Larsson and Jönson, 2018 p. 370). Proponents have warned that equating old age with disability could perpetuate ageist stereotypes of ill health, especially given that around half of EU citizens aged 65 or older have no form of disability (Jönson and Taghizadeh-Larsson, 2009; Georgantzi, 2018 p. 353). Blurring the lines between ageism and discrimination against people with disabilities could result in a failure to adequately tackle the "systemic inequalities" that older people face or to account for the diverse experiences within older age groups (Jönson and Taghizadeh-

Larsson, 2009; Herro, 2017). The rights of older people and the rights of people with disabilities do overlap in some cases, but they must still be considered as two separate topics.

Some scholars of disability and ageing (e.g. Jönson and Taghizadeh-Larsson, 2009; Cahill, 2017; Shakespeare et al., 2019) have argued that the active ageing model in the older people's rights movement downplays the physical consequences of ageing. This downplaying may stigmatise older people who have care needs (Taghizadeh-Larsson and Jönson, 2018 p. 370). From this perspective, the UNCRPD is a human rights instrument that can guide public policy, especially on health and care settings for older people. Accordingly, people in care homes and non-disabled people in society should be treated equally. This area of the literature on human rights for older people in care homes (e.g. work by Jönson and Taghizadeh-Larsson) is discussed in Chapter 6.

The UNCRPD is increasingly being referred to in the debate on human rights laws and policies for people with dementia, especially in relation to the MCA (Cahill, 2017). Dementia has been recast as a human rights topic and a disability under biopsychosocial, social and human rights models. This thesis acknowledges the importance of human rights matters that concern people with cognitive impairments in care homes, but it does not further engage with them. The reasons are given in Chapter 5.

2.4.3 Long-term care and care homes

Chapters 4 and 6 of this thesis explore how human rights in care homes for older people are approached and discussed in the academic literature and the regulatory framework for care homes in England. However, as a contextual point, long-term care in care homes features prominently in the debate on older people's rights, both at the UN level and in the CoE (e.g. Council of Europe, 2017). A mixed-methods study that analysed documents from the OEWGA found that the care of older people, alongside social security and health rights, was one of the most widely discussed topics at OEWGA meetings (Herro, 2017 p. 94).

In the international debate, there are two approaches to the topic of long-term care. The first considers the availability of and the right to access long-term care; the second considers the human rights of older people who live in care homes (e.g. United Nations Principles for Older Persons, ppc. 12 and 14; United Nations General Assembly, 2009 point 4). This thesis is not concerned with the first approach. In the second approach, a common narrative depicts older residents as being especially vulnerable to experiencing ageism and other violations of their human rights in care homes, especially at the hands of caregivers and care workers (e.g. United Nations General Assembly, 2009 point 19). In relevant documents, care homes are sometimes referred to as a form of "institutionalised" care that can harm residents, in particular when considering the importance

attached to autonomy and independence (e.g. United Nations General Assembly, 2012 p. 52). An example of this is contained in Anand Grover's (2011) thematic study for the UN's Human Rights Council on the right to health for older persons. Grover, Special Rapporteur for Health, argued the following:

> The Special Rapporteur stresses the impact of institutionalisation on the autonomy of older persons and its often harmful effect on their dignity… Loss of full independence and, restricted freedom of movement and lack of access to basic functions would cause feelings of deep frustration and humiliation to any individuals …As with other vulnerable and marginalized groups, special attention is needed to protect older persons from abuse and to ensure their rights in settings where they might be especially prone to violations (UN General Assembly, 2011 p. 13).

Kesby's (2017) analysis of active ageing and its role in the debate on human rights and older people (outlined above) would seem to apply in Grover's report, which emphasises related concepts such as autonomy and independence.

Nevertheless, the prominence of people's right to access long-term care options implies that care homes are a significant alternative for care provision in ageing societies to care in the community and at home. In many sources (e.g. United Nations Principles for Older Persons 1991; UN General Assembly, 2015 p. 10; Council of Europe, 2017) the focus is on good practice for continuously protecting residents' human rights, rather than on the potential risks to these rights. For example, the 1991 UN Principles declared that care home residents have the right "to be able to make decisions about their care and the quality of their lives" and the right to have their privacy, needs, beliefs and dignity continuously respected (United Nations Principles for Older Persons 1991, principle 14). A person-centred approach to care, which is defined and discussed in Chapter 3, is often considered good practice for care homes (e.g. Council of Europe, 2017 p. 58).

2.5 SUMMARY

Chapter 2 contextualised and provided a rationale for this human rights research in care homes for older people in England. It explained the levels of protection available for human rights on which England's legal and social policy framework for care homes is positioned. It drew on multi-disciplinary literature to identify the current debates on the human rights duties of state and non-state actors, including private care homes. It introduced the idea of a trickling-down process of transferring human rights duties to non-state actors, which is elaborated on in other chapters. It described England's legal system for protecting human rights in the context of the international and

regional human rights regime, and discussed the public and political climate for human rights in England by referring to socio-legal commentary on recent developments in politics and public policy. The discussion concluded that despite the effects of the HRA on regulatory regimes in England, because of public perceptions of human rights the concept of international human rights is competing with particular values (such as dignity and respect). This is another reason to explore multiple perspectives on the potential role of human rights in care homes for older people. Furthermore, the chapter sketched out the international debate on older people's human rights, in which the topic of care homes features prominently. It argued that in this debate, older people are recognised as equal rightsholders. Thus, this study aims to aid understanding of how people living in, working in and visiting English care homes currently view the potential role of human rights in care homes, and in doing so to "give a voice" to older people and those who care for them.

3 Care homes in England

Chapter 3 puts care homes in England into context, and consists of two parts. Section 3.1 considers care homes in the wider context of adult social care provision and care quality regulation. Frequently descriptive, this section aims to set the scene for the current policy and regulatory context in which care homes in England exist. This is important for analysing and making sense of the human rights framework governing English care homes (Chapter 4). It also explains the background for the CQC data, including inspection reports, that was analysed for this thesis. Section 3.2 focuses on the main characteristics of the care home community, including the people who live in, work in and visit care homes. It aims to draw out the interdependence between people in this community and their potentially complex realities in the wider context of care homes.

3.1 Adult social care provision and regulation in England

3.1.1 The care home market: historical developments in provision and funding

Care homes in England have a long history in politics and law, and there has been a shift from mostly public to independent service provision. Early milestones were the Poor Law enacted in 1834 and the National Assistance Act 1948, which put in place a local authority system of community services and residential homes to help poor older people and those with disabilities or health conditions. The 1948 Act introduced regulation for such accommodation and means-testing to assess residents' ability to pay for a place. Government funding was allocated using population-based formulae. In the 1960s, two-thirds of all residents lived in care homes run by local authorities, and only one-fifth lived in independent care homes (Johnson et al., 2012 p. 255).

In the 1980s, a shift in the Conservative government's policy on financial benefits for care home residents set in motion the privatisation of the market (Johnson et al., 2012 p. 27). At that time, supplementary benefits and national social security regulations meant that low-income residents could claim board and lodging allowances from central government; this incentivised local authorities to accommodate people who needed care and support in care homes. By 1993, 280,000 people were being supported in this way at a cost of £2.6 billion to the central government. The NHS and Community Care Act 1990 was introduced following the Griffiths report (1983) and reports published by the Audit Commission (1986) and the Firth Committee (Department of Health and Social Security, 1987). The Act set a target of shifting 85% of adult services provision from local authorities to the independent sector, prompting the rise of commercial providers. In addition, care home residents could no longer claim financial support from the social security budget on top of the usual pension and disability benefits. Anyone who needed care and support in a residential care home had to approach their local authority for financial assistance, which was based on a financial

means and support needs test. Since then, local authorities have had to pay for publicly funded residential care out of their own budgets.

To clarify, England operates a decentralised system of government. There are 353 local authorities (called councils or boroughs), of which 150 deal with adult social care provision and care homes. Local authorities differ in size and demography, and they operate under an elected local government. Their finances rely on central government funds and council tax paid by residents and businesses.

As of 2019, there are around 20,000 care homes (residential and nursing) in England providing services for people aged 65 or older. The market is estimated to be worth £16.9 billion in Britain (LaingBuisson, 2018). Now, 76% of care home places are provided by for-profit companies (Jarrett, 2018 p. 2. Another 8% are held by local authorities, and the rest by not-for-profit providers. In comparison, in 1984, local authorities owned 57% of all care home places (Jarrett, 2018 p. 2. The four largest private care home providers in England hold around 15% of all care beds (LaingBuisson, 2016 p. 20). However, around 70% of the care home market is made up of smaller providers that run up to three care homes (Jarrett, 2018 p. 3). Even though a shortage of beds in English care homes has been predicted in the next few years, research by care market analysist LaingBuisson (2018) suggests that care homes currently run at only 85% of their capacity.

Local authorities must have systems in place to assess users' needs and finances and allocate financial support to individuals who own assets of £23,250 or less (Age UK, 2018). Therefore, residents of care homes (with or without nursing) may be self-funded or be means-tested by the local authority to receive public support with their fees. The NHS meets some costs for some nursing home residents (Jarrett, 2018). Around 41% of care home residents pay for their stay privately, 12% receive top-ups from local authorities and 37% have their stay paid for in full by local authorities (LaingBuisson, 2016; Jarrett, 2018). Some care home groups, including the four biggest ones, operate business models based on a mix of publicly funded and private residents. Under this system of funding social care, many care home providers depend on local authorities and their willingness to pay fees that are adequate for providing high-quality care (Jarrett, 2018).

In recent years, local authorities have seen a deficit in public funding for adult social care, including care homes. The Local Government Association (2019) estimated that adult social care services would face a £1 billion funding gap by 2019/2020, and a £3.6 billion gap by 2024/2025. Fees paid by local authorities to care home providers fell by 6% between 2010/2011 and 2016/2017 (Jarrett, 2018 p. 4). Combined with cuts in social care funding, these reductions have left many care homes needing to make efficiency savings (CQC, 2016). Between April 2017 and April 2018, the number of

residential care homes fell by 2.4%; most of those that closed down were small. The CQC has suggested that the financial and resourcing pressures above are a major cause (Burns et al., 2016; CQC, 2018a p. 57). In addition, allowing care homes to set the rates for self-funded residents has led to a system of cross-subsidisation, in which private residents subsidise the lower rates paid on behalf of publicly funded residents. At times, private residents pay double for the same services provided to publicly funded residents (Competition and Markets Authority, 2018a). The difference between privately and publicly funded residents translates into the human rights framework governing English care homes (see Chapter 4).

3.1.2 Regulating care quality

The quality of care services, including in care homes, has been a concern since the landmark study by the sociologist Peter Townsend, 'The Last Refuge' (Townsend, 1962). Townsend highlighted the poor quality of care and services in care homes and advocated for developing community-based alternatives. The rise of independent care homes in the 1980s, with their variations in service quality, fuelled this concern and eventually led to the Registered Homes Act 1984. This laid the ground for today's system of care quality regulation and inspection.

The policy of focusing on a mixed economy of care providers addressed service quality by creating consumer choice, which incentivised providers to deal with any concerns (Hirschman, 1970; Trigg, 2018 p. 18). However, even though it is recommended that people have choice and control over their care homes from the perspective of human rights (Scourfield, 2007), in reality many people needing care and support either have a limited ability to express their wishes or find that their preferred care home is not available (Trigg, 2018 p. 18). Therefore, policies that rely on care home residents being "autonomous, rational and self-serving individuals" do not adequately reflect the reality (O'Rourke, 2015 p. 1010).

The NHS and Community Care Act 1990 established the need for local authorities to build local registration and quality inspection mechanisms for all care homes. However, due to the inconsistency in regulatory mechanisms across local authorities, a national inspectorate for the registration, regulation and inspection of care homes was established in 1997. This was called the National Care Standards Commission (NCSC). In 2008, the Health and Social Care Act came into force and the NCSC was replaced by the CQC. The section below discusses the current understanding of "quality of care" in care homes. The CQC as the main regulator for care quality is then introduced.

3.1.2.a Defining quality of care

Reed (2007) defined quality of care in care homes as "the way care is delivered and the standards that it meets" (Reed, 2007 p. 24). However, it is also an elusive and dynamic concept, because it

depends on the constructed meaning of "quality" and the definition of "care" in a caring relationship between care workers and residents. As Davies and Heath explained:

> The concept of quality is elusive because definition relies upon value judgement. The term "quality of care" is dynamic because what is considered to be of high or low-quality changes over time and across settings to reflect prevailing social values of health and illness and also the expectations that people hold of services and practitioner-user relationships (Davies and Heath, 2007 p. 30).

Quality of care must be distinguished from "quality of life". In the relevant academic literature, the two concepts are often seen as related yet distinct. Quality of care frequently focuses on care delivery (such as support with ADLs), whereas quality of life (in the context of care homes) encompasses individual subjective perspectives on multiple factors that influence well-being (Reed, 2007). Quality of life may include care quality as one factor amongst others. Other factors frequently identified in the academic literature include the environment, meaningful activities, and positive interactions (thus, good relationships) with people inside and outside the care home. Of course, interactions between care workers and residents can also be understood as relationships, which again highlights the inter-relatedness of quality of life and quality of care.

The concepts of "person-centred care" and "personalisation" have influenced the existing policy, legal and regulatory framework governing quality of care in the residential care sector. Person-centred care has been an underlying principle of the National Service Framework for Older People since 2001, when the first national set of service standards for older people in England was introduced (Manthorpe and Samsi, 2016). Person-centred care and personalisation can both be linked to the movement for the empowerment and participation in decision-making of people with physical and cognitive impairments and those who need care and support (Woolham et al., 2015). Personalisation often drives debates on consumer choice about care services, whereas person-centred care is mainly about maintaining identity and dignity through needs and preference-based provision of care services (Leplege et al., 2009).

The concept of person-centred care is rooted in Tom Kitwood's (1997) model for dementia care, which he adopted from the American psychologist Carl Rogers (Rogers, 1942; 1951). The concept emphasises the centrality of maintaining the "personhood" or "selfhood" of individuals who are affected by dementia and need care and support (Fazio et al., 2018). According to Kitwood (1997 p. 8), personhood is "a standing or status that is bestowed upon one human being, by others, it implies recognition, respect and trust". On this basis, concepts such as choice, autonomy and

participation have increasingly shaped the current definition of high-quality care in care homes (Stevens et al., 2013). By law, care homes must provide person-centred care to all residents, whether they are affected by dementia or not (e.g. Health and Social Care Act (Regulated Activities) Regulations 2014, Regulation 9, "Person centred care"). Many care homes have introduced mechanisms to translate person-centred care into practice. One example is the biographical approach, in which a resident's life before moving into the care home shapes the way care is provided inside the care home; another example is continued participation in care planning (Bridges, 2007).

Other approaches to understanding quality of care have emerged. Nolan's relationship-centred care model, the Senses Framework (Nolan et al., 2006), has strongly influenced care home providers' definition of high-quality care (Trigg, 2018). The Senses Framework is founded on developments in the American healthcare system the 1990s, when positive interactions amongst people were increasingly recognised as being at the centre of any high-quality therapeutic or healing activity (Nolan et al., 2004 p. 48). Adopting this basic premise, Nolan and colleagues researched the elements of positive relationships in care homes. They argued that these relationships should be experienced not only by care home residents in their interactions with care workers, but by care workers in their interactions with caring family members of residents, because these groups of people are inter-related and interdependent. They proposed that good relationships experienced by all people in care homes should promote the following six senses: security, belonging, continuity, purpose, achievement and significance. This framework "captures the subjective and perceptual dimensions of caring relationships and reflects both the interpersonal processes involved and the intrapersonal experiences of giving and receiving care" (Nolan et al., 2004 p. 49).

Quality of care and quality of life in care homes can be interlinked. Positive interpersonal relationships between residents, care staff and other people in care homes emerges from the literature as an aspect that influences residents' experiences. This blurs the line between the two approaches to quality. Kitwood too acknowledged that trusting relationships between the provider and recipient of care are essential for maintaining the "personhood" of the person receiving care, because through these relationships "selfhood is continually evoked and reassured" (Fazio et al., 2018

Furthermore, long-term civil society initiatives aim to bring about a collective culture change in care homes on the basis of a pre-defined understanding of what quality of care entails. As is evident in Chapters 4, 6 and 10 human rights language is increasingly used in discussions about existing

conceptualisations of quality of care and their significance in today's care homes, particularly in relation to person-centred care.

The care quality regulation system

Local authorities play a role in care quality regulation under the Care Act 2014 (see Chapter 2). They are also responsible for shaping the market; that is, for ensuring that enough adult social care services, including care homes, are available for people in their area to be able to make a choice about which care service they use (Department of Health and Social Care, 2017b). To achieve this, local authorities allocate funds to a variety of services through adult social care commissioning. Local authorities also work with the CQC to monitor the financial stability and quality of large care home providers. If a provider fails, the local authority must step in and ensure that residents continue to receive the care and support they need (Care Act 2014 s.48(2)). The CQC, rather than local authorities, is responsible for monitoring and inspecting the quality of care services. The following background on the CQC's role is important for Chapter 7, which discusses the development of the organisation's human rights approach.

The Care Quality Commission as the regulator of quality standards in care homes

The CQC is a non-departmental public body. It is sponsored by the Department of Health and Social Care and is accountable to Parliament and the Secretary of State for Health and Social Care. It has a board, an executive team and a complex sub-structure for organisational management, strategy development and fulfilling its main purpose.

The CQC regulates adult social care, general practice and hospitals. There is a chief inspector for each of these sectors, and each chief inspector is a member of the executive team and the board. The chief inspectors head teams of inspectors, who visit and rate care homes and other services. There is also a Director for Strategy and Intelligence, who leads a large team of internal strategy and policy consultants. In 2016/2017, the CQC's operational expenditure was £222 million (National Audit Office, 2017). As of September 2018, the CQC employed 3362 people, of whom 1438 were inspectors. Of these, 815 were inspectors of adult social care services, including care homes.[1]

The CQC's objective is "to protect and promote the health, safety and welfare of people who use health and social care services", and its purpose is to encourage improvement in the quality of health and social care services in line with service users' needs and experiences and the efficient use of resources in care services (Health and Social Care Act 2008, s.3(1)). On its public-facing website,

[1] According to a response from the CQC on 18 September 2018 following the researcher's request under the Freedom of Information Act 2000 on numbers of employees.

the CQC declares: “We make sure health and social care services provide people with safe, effective, high quality care and we encourage them to improve” (CQC, 2019a).

The CQC is responsible for registering all providers of health and social care. Anyone who wants to provide regulated activities, such as personal care and healthcare for older people, must register with the CQC; if they fail to do this, they are committing a criminal offence (CQC, 2019b). After registering, the provider must comply with the CQC’s regulations and is monitored accordingly. Currently, the CQC regulates around 49,000 hospitals, primary medical services and adult social care providers in England’ (National Audit Office, 2017).

The CQC also publishes reports on “major quality issues regarding health and social care” (CQC, 2019a). The organisation can apply enforcement powers to the services it monitors and inspects. It can, for example, issue “special measures” (CQC, 2019b). A care home issued with special measures must put in place specific improvements within a limited time: usually up to six months. The CQC can also close a care home if its standards of care consistently fail inspections. In 2017/2018, the CQC forced 141 providers to close, of which 78% were adult social care services, including care homes (CQC, 2018a). However, closing a care home can severely affect residents’ well-being and the continuity of their care, so it is a last resort (CQC, 2018a).

The CQC also receives safeguarding concerns about registered services from the public or whistle-blowers. It can directly prosecute services who have harmed their service users or failed to register with the CQC. Since 2015, the CQC has been able to make criminal charges against individuals operating or managing care services, and it has done so several times (CQC, 2019c).

The CQC is not an improvement agency (Smithson et al., 2018 p. 11). Rather, it identifies potential problems with quality through inspections, which must then be resolved by the providers and other organisations in the social care system, such as local authorities. Accordingly, “[The CQC’s] inspections diagnose issues in health and care providers, and it catalyses other parts of the system to take action. This means that the CQC’s impact is dependent on others supporting providers to improve” (Smithson et al., 2018 p. 11).

In her study on care home regulatory mechanisms in England and Australia, Lisa Trigg argued that the CQC operates a deterrence-based system of regulation, whilst the Australian system is based on compliance (Walshe and Phipps, 2013; Trigg, 2018 p. 38). Major differences between these systems include the regulator’s approach to service providers and service users, and the relationship between the regulator, service users and care providers (Trigg, 2018). Whilst the English CQC considers care service providers as inherently “amoral and self-interested, the Australian one

approaches providers as altruistic and political citizens" (Trigg, 2018 p. 38). This is reinforced by differences in how problems are identified and highlighted publicly and the sanctions that are available and used against providers in the two contexts (Trigg, 2018 p. 38). Indeed, at the heart of the CQC lies protecting the service user against violations of quality standards by their care service providers. As argued in Chapter 7, this core purpose makes it difficult to translate human rights into the CQC's work, because it cannot inspect for breaches of human rights violations in care homes under the HRA.

After the CQC was established in 2009, it suffered several setbacks in its operations, leadership and public image. The deterrence-based system developed out of this (Trigg, 2018). In 2011 and 2012 in particular, the National Audit Office, the Public Accounts Committee, the Department of Health and the Francis Report (Francis, 2013) all criticised the CQC's operations and leadership. They reported that the CQC had consistently failed to meet registration deadlines, missed targets for inspecting care services and lacked the skills and capacity to carry out its purpose fairly and consistently (National Audit Office, 2011). This coincided with care service scandals in the media, notably the case of Winterbourne View Private Hospital and an episode of the BBC's *Panorama* series, "Behind Closed Doors", which uncovered neglect and abuse of residents in English care homes (Manthorpe and Samsi, 2016). The CQC responded with a change in leadership and put in place strategies to improve its performance; these included recruiting skilled employees and setting up specialist inspection teams for hospitals, primary and integrated care services, and adult social care (House of Commons Health Committee, 2014). These developments provided the basis for the CQC's human rights approach to regulating care services (see Chapter 7).

Although the National Audit Office (2017) found that the CQC was fulfilling its purpose more effectively, it also noted room for improvement. For example, the CQC did not always alert inspectors within the prescribed five working days of receiving an adult safeguarding concern. Stakeholders found inconsistency in the CQC's regulatory judgements when rating services, and they cited examples of inspectors being too subjective. Although the purpose of this thesis was not to test the CQC's human rights approach to care home inspections, Chapter 7 discusses the use of human rights language in the inspection reports collected for this study.

Regulating, monitoring and inspecting quality standards

The CQC monitors services in line with certain standards. Between 2009 and 2015, these standards were called Essential Standards of Quality and Safety and were applied generically to all regulated services on a compliance or non-compliance basis. This resulted in "fairly superficial inspections" of care services (Smithson et al., 2018 p. 6). In 2015, the essential standards were replaced by 13

fundamental standards, which the CQC defines as “the standards below which your care must never fall” (CQC, 2019d). These standards are enshrined in the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014.

In performing its monitoring function, the CQC inspects care home services for compliance with the fundamental standards. These inspections take place at least once every five years (CQC, 2018c) and are conducted by at least one CQC adult social care inspector. The fundamental standards are accompanied by five “quality domains”, a system of quality ratings and key lines of enquiry (KLOEs) that provide the basis for the inspections (CQC, 2017b). This method aimed to make the system more understandable for staff, the public and commissioning organisations, such as local authorities (CQC, 2015). The five quality domains are framed as questions (see Table 3.1). Inspectors assess each question using the KLOEs framework, which gives them specific points to look for under each quality domain. A detailed description of the inspection mechanisms here is important for later chapters, particularly Chapter 7.

After inspecting a care service, the inspectors produce a report and give the service an overall rating and one of four ratings for each quality domain. The ratings are “outstanding”, “good”, “requires improvement” and “inadequate”. Across all registered residential care homes in England, 77% are rated as “good”. Of the remainder, 3% have a rating of “outstanding”, 2% have a rating of “inadequate” and 18% have a rating of “requires improvement” (CQC, 2018a). These percentages correlate roughly with ratings of other adult social care services, including care homes with nursing, of which 25% have a rating of “inadequate” and 69% are “good” (CQC, 2018a p. 59).

The inspection reports also describe the inspector’s observations of and findings on life in a particular care home. They include instances of poor care or good practice that came to the inspector’s attention during the visit. Such good or poor practice may be reiterated in other CQC quality reports and blogs, which are also analysed in this thesis (see Chapter 5). The inspection reports also include recommendations for improving the service. The reports are published on the CQC’s website, and care homes must disclose their CQC rating to the public as part of their compliance with the fundamental standards and to empower consumers choose a care service provider (CQC, Standard 13). However, the purpose of publishing the reports may also be to encourage providers to improve quality (Trigg, 2018 p. 165). Thus, ratings and published reports – including the acknowledgement of poor and good care practice – form an important part of the CQC’s deterrence-based strategy (Trigg, 2018).

Table 3.1 Foundation of the CQC's inspection mechanism

Fundamental standards	Inspection quality domains	Ratings
Person-centred care	Is the service safe?	Outstanding
Dignity and respect	Is the service caring?	Good
Consent	Is the service effective	Requires improvement
Safety	Is the service responsive to people's needs?	Inadequate
Safeguarding from abuse	Is the service well led?	
Premises and equipment		
Complaints		
Good governance		
Staffing		
Fit and proper staff		
Duty of Candour		
Display ratings		

Recent research has highlighted the role and impact of CQC inspection mechanisms and ratings on care homes (Smithson et al., 2018). This provides some insight into the relationship between care homes and the CQC, which is relevant in parts of Chapters 7 and 10.

Smithson and colleagues (2018) researched eight types of regulatory impact that CQC inspections have on health and social care providers. The "anticipatory impact" of CQC inspections is the most extensive of these. Here, providers seek to comply with the regulator's expectations of quality before any regulatory interaction takes place (Smithson et al., 2018 p. 18). In practice, services such as care homes read CQC guidelines with a view to understanding what is expected of them and then check their own performance against such guidance through peer review systems or mock inspections (Smithson et al., 2018 p. 18). Often, however, anticipatory activities do not focus on integrating CQC regulations into care home processes in a sustainable way; rather, they frequently seek "to achieve superficial or ritual compliance" with a view to scoring a high rating (Smithson et al., 2018 p. 18).

Trigg highlighted the detrimental effect of a low CQC rating on a care home, especially on its reputation and funding: "Low ratings are a self-fulfilling prophecy: once a provider is badged as

inadequate, staff start to leave, and no new residents enter the home and the home quickly goes downhill" (Trigg, 2018 p. 164). Anticipating CQC inspections causes anxiety and stress amongst care home staff due to a lack of clarity about expectations and the possibility of being given a poor rating (Smithson et al., 2018 p. 18). This is exacerbated by the widespread perception that CQC inspectors are subjective and lack consistency when visiting and rating care homes (National Audit Office, 2017; Smithson et al., 2018).

Regarding other types of impact, CQC inspections can lead to organisational developments if the care home is capable of responding to inspections and improving. This may include a change in leadership after a poor rating or the introduction of a new organisational culture (Smithson et al., 2018). However, these changes are generally not attributable to recommendations in the CQC inspection reports. This agrees with Trigg's (2018) research into care home providers. She argued that although inspection mechanisms encourage providers to improve, providers' behaviour regarding their residents' quality of life is not closely connected to CQC inspections. Rather, it stems from "the intrinsic motivation of providers to maximise the quality of life of their residents" (Trigg, 2018 p. 208). Thus, a care home manager's leadership and management style may have more influence on the quality of a care service than CQC inspections do.

3.2 People living in, working in and visiting care homes

This section introduces some information about people living in, working in and visiting care homes. Here, care homes are approached as communities of people, in which individuals interact. Many of these interactions can be understood as caring relationships, as defined in Chapter 1. Those relationships are often recognised as central to quality of care and the quality of life experiences for care home residents, staff and visiting relatives. Interactions may be influenced by subjective interpersonal and intrapersonal factors, which in turn are shaped by personal experiences, an individual's role in a care home and other factors (e.g. Brown-Wilson et al., 2009).

Several studies on the characteristics of personal relationships in care homes have suggested that different types of relationships exist. Brown-Wilson and colleagues (2009) identified that relationships between residents, care home staff and families can be "pragmatic", "personal and responsive" or "reciprocal". Reciprocal relationships were argued to be the most effective in building trusting relationships between residents, staff and family members. These relationships are based on negotiation and compromise between the three groups and the recognition of all individuals in the relationships: "The focus of [reciprocal] relationships moved beyond the resident to recognise the needs of family members and staff as individuals that could all make valued contributions" (Brown-Wilson et al., 2009 p. 1053).

To clarify, in this chapter "communities of people" means a group of individuals whose uniting factor is their shared affiliation to a particular care home, either through living in the care home, working in it or visiting it regularly. Some academic literature proposes creating care homes as communities with a shared consciousness, designated roles and so on; however, this chapter does not aim to propose or develop such an ideal. Rather, it introduces what is known about the actors in care homes and conceptualises them as communities that bring these actors together under one roof. In doing so, it highlights the complex context in which relationships between care home residents, their relatives and care home staff unfold.

3.2.1 Care home residents

This thesis has already covered much of what is known about care home residents; for example, in discussions around the future need for care homes (Chapter 1) and definitions of care quality (Section 3.1). This is because any engagement with care homes for older people is extrinsically linked to the residents, without whom care homes would not exist. Chapter 5 describes the key demographics of the care home population, which determined some aspects of the methodology. This section provides a summary of some of the intricacies of the reality for many residents.

Older people aim to stay at home for as long as they can, so those who move into a care home tend to have increasing health and support needs (Green et. al, 2018). Such a move is often associated with fear, which is related to stigmas and negative images of care homes (The Commission on Residential Care, 2014). Moving into a care home can harm an older person's self-identity by disconnecting them from their previous routines, social networks and interests (Paddock et al., 2018). A change in self-identity can make it difficult for residents to settle in to care home life. Furthermore, an increasing reliance on care home staff can affect older residents' autonomy and independence (Paddock et al., 2018): an argument that is frequently adopted by those who take a human rights approach to care homes. Some studies have considered the prevalence of ageism and other forms of discrimination in care homes, which may emerge in relationships between residents and in the interactions between residents and care workers or relatives (see Chapter 2). However, others (e.g. Nolan et al., 2004) have suggested that life satisfaction in care homes can be improved through positive relationships between residents and others in the community, nurturing care home cultures and certain environmental factors. Of course, the CQC and local authorities have a duty to work towards a better quality of care and a stronger sense of well-being amongst people in care homes.

3.2.2 Care home staff

Care homes may employ care workers, managers, activity co-ordinators and kitchen and maintenance staff. In England, residential care homes employ around 305,000 people across 11,650 sites (Skills for Care, 2018b). Of this workforce, 225,000 are employed as care workers and 30,000 hold managerial jobs (Skills for Care, 2018b).

Care workers are usually the people who provide residents' care, including support with ADLs such as washing, dressing and taking medication (Hussein, 2017; National Careers Service, 2018). The term "care worker" excludes people in "regulated professions", such as registered nurses or occupational therapists (Skills for Care, 2018b). Activity co-ordinators, administrative staff and handymen are not usually considered to be care workers, although in practice many of them perform some activities associated with social care at times, especially when there is an acute shortage of staff.

Care home managers are responsible for the leadership and management of the care home. They must ensure that the care home meets the required standards (National Careers Service, 2018). Under the Health and Social Care Act 2008, usually care homes must register the care home manager with the CQC (CQC, 2017). To have their registration approved, the applicant must show that he or she is of "good character", has the "necessary qualifications, competence and skills to manage the carrying out of registered activities" and is mentally and physically healthy (Health and Social Care Act 2008, s.7(21a-c)).

3.2.2.a Key challenges faced by care home staff

To meet exemplary standards of care quality, a care home must have a workforce of an appropriate size, who are well-trained and healthy (Eaton, 2000; CQC, 2016). English care homes are under pressure in this respect. Due to a widening gap between demand and public spending, they face difficulties in recruiting and retaining staff (Moriarty et al., 2018 p. 7). Each year, around 26% of care workers in England's residential care organisations leave their jobs; in 2017, around 5% of care home staff vacancies (16,000 vacancies) were unfilled (Skills for Care, 2017; 2018a). Many consider the sector unattractive: it offers low pay at the front line of care, yet places high demands on employees (Cavendish, 2013; Hussein, 2017). The key challenges that care workers encounter are as follows.

Care workers usually have a wide range of tasks to work through, often in a set timeframe. This can reduce their job satisfaction and morale (Razavi and Staab, 2010; Moriarty et al., 2018). The job is also often emotionally and physically challenging, which can lead to health-related time off work (Baker et al., 2015). Academic studies have mentioned, for example, the negative effects on care workers' health from the physical stresses associated with care tasks, such as heavy lifting or

bending for prolonged times (Graham and Dougherty, 2012). Furthermore, working with people who are at the end of their life or have advanced medical conditions (or both) can be emotionally stressful (Katz et al., 2001). Studies have focused on emotional and physical stress amongst care workers who work with people who have dementia, who often behave differently from people without a cognitive impairment (Zimmerman et al., 2005; Lann-Wolcott et al 2011; Baker et al., 2015; Islam et. al, 2017). Care workers who lack dementia-specific training may find it particularly difficult to respond to people with severe dementia (Islam et al., 2017).

Some care workers may face other challenges linked to mental and physical well-being. For example, a study by Stevens and colleagues (2012) investigated the experiences of racism and discrimination amongst care workers who were recruited from outside the UK or had migrated to the UK. The authors found that these care workers sometimes experience racist comments and rejection from people managing and living in care homes (Stevens et al., 2012 p. 259).

It is not only care workers who may have to deal with stress. In a scoping review of the literature on care home managers, Orellana and colleagues (2016) found that the manager's role is also linked to several stress factors and the feeling of being undervalued and unsupported (Chambers and Tyrer, 2002; 2003; Chambers, 2003; Orellana et al., 2016). Care home managers are concerned about being able to provide a homely, person-centred care environment in times of financial constraint and difficulties in retaining staff. They experience external negativity towards care homes, excessive bureaucracy and constant changes in requirements; in addition, they have substantially higher levels of responsibility and legal accountability than is required by the Health and Social Care Act 2008 (Orellana, 2014; Orellana et al., 2016).

3.2.2.b Training

In England, it is largely down to care home providers, care homes and their managers to support and encourage staff to receive training. In theory, care workers do not need professional qualifications to work in a care home. However, since the Cavendish Review in 2013 (Cavendish, 2013), care workers have been able to gain a "care certificate" and five levels of diploma qualifications. Around half of care workers in all care settings hold an adult social care qualification, 49% at diploma level 2 or above (Skills for Care, 2018a, Executive Summary). Furthermore, in recent years government policy has been pushing for developing a more skilled care workforce with more opportunities for career progression (Moriarty et al., 2018). Consequently, new training models have appeared, such as apprenticeship schemes that provide on-the-job training. There is currently a lack of knowledge about the value and success of such schemes for providers and their staff (Moriarty et al., 2018). Although this thesis does not aim to investigate human rights in the training curriculum, some care

workers who were interviewed mentioned that they had undertaken “human rights relevant training”.

Training and development for agency care workers is overseen by their agency employers. However, in a study on agency and temporary care staff, Manthorpe and colleagues (2012) reported that some employers fail to give their staff opportunities for professional development and training. The lack of training may compromise their ability to offer continuity of care, which directly influences the quality of care provided in a care home.

Care home managers need a large skill set to be able to perform their tasks (Addison and Bunce, 2013; Orellana et al., 2016). As part of registering with the CQC, they must demonstrate that they have the “relevant” training and qualifications for managing a care home (CQC, 2019e). Although this can include a level 4 diploma or above, it is not a requirement. As is the case with care workers, training opportunities for care home managers depend on the initiative of the care home providers and owners.

3.2.2.c Contracts and pay

Around 50% of all care workers in care homes are employed full time. Of this workforce, many are on a zero hours contract, with no set timeframe for their work. Care homes often fill short-term vacancies with agency-employed care workers (Manthorpe et al., 2012). The average hourly pay for care workers in care homes is between £7.97 and £8.85 (Skills for Care, 2018c). Research conducted by Hussein (2017) highlighted the persistence and severity of low wages for front-line care workers in care homes and in other settings (Hussein, 2017; Moriarty et al., 2018). According to this research, 10%–13% of care workers earn less than the national minimum wage.

Besides the economic climate of the care home market, social factors have been linked to the low pay of care workers. These factors are often understood as inherent in the job (Duffy, Albedla and Hammonds, 2013; Hussein, 2017). The caring role is frequently seen to involve self-sacrifice on the part of care workers, and enjoyment is perceived to be derived from providing care rather than earning high wages (Hussein, 2017). Some research suggests that discrimination on the grounds of age and disability contributes to the persistence of, and justification for, low wages in the sector (Hussein, 2017).

3.2.3 Family members and others in the care home environment

The care home environment includes visitors and members of the wider community in which a care home is situated (Froggatt, 2008). Visitors include volunteers, religious leaders, healthcare professionals, advocates, and residents’ family. Although all these groups – and many more – can

play an important role in the care home community, only a short summary is provided here for reasons of space and relevance.

The relevant literature suggests that relatives of care home residents experience an "emotional journey", which is influenced by complex relational dynamics in the family and in the care home. This journey often begins before a family member moves into a care home, continues with their life in the care home and ends when the person dies, or sometimes even long after that. For example, in a systematic literature review that explored the "optimal" time for people with dementia to move into a care home, Cole and colleagues (2018) explained the situation of family carers in the lead-up to such a move. They highlighted that family carers often feel unable to cope any longer with their older relative's condition, which triggers their choice to move them into a care home. People with dementia are often a passive agent in this decision (Cole et al., 2018 p. 1660). Those relatives with negative perceptions of care homes tended to consider a care home as a last resort, so deciding on such a move can trigger negative emotions, such as feelings of guilt and failure (Cole et al., 2018 p. 1662). This mirrors the research into effects on self-identify when a person moves into a care home. Nevertheless, Cole and colleagues also points out studies in which family members felt positive about their older relative's move and had a heightened sense of their relative's safety and well-being.

Puurveen and colleagues (2018) studied the academic literature on family involvement in nursing homes. They suggested that family members of residents usually take on regular substantial support roles, even after the move into a care home. This includes "hands-on assistance" with ADLs, managing or overseeing care by care workers, and providing socio-emotional support for their family member and other residents (Puurveen et al., 2018 p. 7). The authors argued that this involvement is mostly rooted in relatives' wish to contribute to their family member's well-being and the quality of care they receive in a care home, and that it is rooted in complex relational dynamics (Puurveen et al., 2018 p. 9). The same authors summarised the literature on relationships between staff and families, from which challenges and potential entry points for conflict emerged (Puurveen et al., 2018). Family engagement in care homes is not always supported by staff, who, in a complex web of power dynamics, may feel the need to negotiate care and consider such engagement as an additional burden. Families, on the other hand, may experience stress and strain if they perceive the quality of care as substandard and do not feel included in decisions that affect their relative (Puurveen et al., 2018 pp. 16–25). This can lead to miscommunication and conflict between families and care home staff. On the other hand, some studies (e.g. Brown-Wilson, 2009) have highlighted that reciprocal relationships between staff, residents and family members can contribute to a

perceived higher quality of care and quality of life for care home residents and others in the care home community. The end of a care home resident's life is an emotional and potentially traumatic experience for their family members. How care home staff deal with this, and how they communicate with family members, is crucial to their experience.

3.3 SUMMARY

This chapter aimed to provide more context to the subject of human rights research in care homes for older people in England. It introduced some of the major actors in the care home system, including local authorities, the CQC and the care home community. Furthermore, it highlighted some of the complexities underlying the relationships between these stakeholders. These include interactions between care homes, the CQC and local authorities, which have been shaped by historical developments in care home provision and regulation. They also include interactions between people inside care homes, all of whom have their own realities, such as physical decline, work and family pressures, and perceptions of themselves and others (including ageist and other discriminatory mindsets). The following chapter, which is the final component of Part I, describes the human rights framework governing English care homes. In doing so, it reveals another level of complexity, which is rooted in traditional conceptions of human rights obligations.

4 The human rights framework governing English care homes

This chapter discusses the human rights obligations of care home providers and staff under the regulatory regime that governs English care homes (henceforth, the human rights framework for English care homes). One such component, the CQC's human rights approach to regulating care homes, was a subject of inquiry in this research; therefore, the findings are tackled in depth in Part II (Chapter 7). In this thesis, the term "regulatory regime" refers to (1) the relevant laws and regulatory measures enforced through the CQC; and (2) adult social care policy papers published by the CQC and government departments, especially the Department of Health and Social Care, between 2010 and 2018. The term "care home provider" refers to CQC-registered providers of care homes as a regulated activity. Care home providers may be a group that owns and runs several care homes or an individual who operates a small number of care homes or just one. A registered care home provider may also be a registered manager (CQC, 2019f).

Long-term care in care homes is part of the international debate on older people's human rights (see Chapter 2). Here, care homes are frequently seen as inherently risky places for human rights, particularly liberty, privacy and freedom from inhumane and degrading treatment (e.g. UN General Assembly, 2011). There is a lack of evidential human rights research into the prevalence of abuse and violence, and the violation of rights, in English care homes. However, many studies suggest that human rights issues and violations persist in care homes (Johnson et al., 2012; Stevens et al., 2012; Tingle, 2012; Stevens et al., 2013; São José et al., 2017). Examples include ageism and the abuse and neglect of residents (and, at times, care workers). Taking this into consideration, the following sections describe how the regulators in England have negotiated their status as the main duty-bearers under human rights law with the reality of a largely independent care home market, which has blurred the public/private divide. The human rights framework for English care homes is both the result and an example of the trickling-down process of transferring human rights obligations to non-state actors: in this case, independent care homes, as explained in Chapter 2. However, this chapter argues that the framework is ambiguous and unclear about care home providers' human rights obligations.

The regulatory regime for social care in England is complex and fragmented (Harding, 2017b p. 3). It applies across all adult social care settings and can be interpreted to include many Acts of law: the Care Act 2014; the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014; the MCA 2005; and health and safety laws. It also includes many public policy documents from various government agencies, including the CQC and the Department of Health and Social Care.

It is beyond the scope and purpose of this chapter to define the exact remit of this regime. Rather, through analytical description, it seeks to establish that under this regime care home providers and staff in England have three grades of legal responsibility regarding human rights, in addition to a social expectation that they will protect those rights. Furthermore, the regime has created two types of care home residents: the "public resident" and the "private resident". The two types have different access to the HRA as a legal remedy for human rights violations in care homes (see Table 4.1 and Section 4.1 for details). This discrimination between two types of residents under human rights law is the result of differences in their financial means (Meenan, 2016 p. 117). It can be interpreted as a breach of Article 14 of the ECHR (prohibition of discrimination). For the purposes of this thesis, it is interpreted in that way.

At the same time, there is a lack of research into access to justice, the availability of legal aid and advocacy services for care home residents, and the number of cases brought against care homes on the basis of the HRA and the Equality Act 2012. However, some brief research into case law regarding the HRA and care homes undertaken for this study suggests that legal claims are uncommon. It has been argued that these claims are unlikely to arise – even for public residents – due to legal complexity, lack of access to legal aid, and personal stress (Harding, 2017a p. 155). Whether the framework can protect human rights is determined not only by the acknowledgement of human rights responsibilities in law, policy and regulation but also by individuals' complex realities and relationships.

The next section describes the three grades of legal human rights responsibility (see Table 4.1). Further sections in this chapter consider the normative framework for human rights obligations in care homes by drawing on relevant adult social care policy papers and the UNGPs.

Table 4.1 Care home providers' human rights obligations

Care home providers' three grades of legal obligation for human rights		
Grade of obligation	Type of liability	Duty-bearers
Grade 1	Directly legally liable under the Human Rights Act 1998	Care home providers housing people whose care has been arranged or is paid in full/in part by a local authority
Grade 2	Indirect responsibility for human rights under the CQC's human rights approach to regulating care homes. Indirect legal responsibility under human rights-oriented Acts of law, including the Equality Act 2010 and the Mental Capacity Act 2005	All care home providers, care home staff
Grade 3	Indirect legal responsibility for human rights through "rights-relevant laws" such as Health and Safety, Data Protection and Consumer laws	All care home providers, care home staff
Care home providers moral obligation to protect human rights		
UNGPs	"Moral obligation to protect human rights"	All care home providers
Public policy papers	Moral obligation to respect human rights	All care home providers, care home staff
Types of care home residents as holders of human rights		
Type 1 resident: Public residents, i.e. those whose care has been arranged and/or is paid for in full/part by a local authority	Access to HRA as legal remedy in court, access to Local Government and Social Care Ombudsman, access to courts on basis of other laws, access to CQC, internal complaints	
Type 2 resident: Private residents, i.e. those whose care has been arranged for and is paid for privately	Access to Local Government and Social Care Ombudsman, access to court in basis of laws other than HRA, access to CQC, internal complaints	

4.1 The three grades of legal obligations

The components of the human rights framework governing English care homes are relevant laws, CQC regulations, and adult social care policy. Under this framework, care homes have three grades of legal responsibility for human rights, and there are two types of care home residents. This section explains the three grades in depth.

Grade 1: Direct legal liability under the HRA

The HRA applies to public authorities across the UK (see Chapter 2). It requires them to act in line with the rights and freedoms in the ECHR (HRA 1998, s.6). Although independent care homes do not automatically fall under the obligations of the HRA, the landmark legal case of *YL v. Birmingham City Council* in 2007 set in motion a development in the law. Under Section 73 of the Care Act 2014, care home providers – even independent ones – are now considered "to be exercising a function of public nature" and are thus directly liable under the HRA. In the case mentioned above, a care home resident with dementia attempted to fight eviction from her care home – owned by a private company – on the basis of the HRA and Article 8 of the ECHR: the right to respect for private and family life. She argued that her eviction would result in her husband and family having to travel longer distances to visit her, making those visits increasingly difficult. Most of the judges in the case decided against the claimant, because her care home was privately owned and could not be considered a public authority under the HRA. In the House of Commons debates that followed, several politicians expressed concerns about the differential treatment of individuals who receive public support from private contracted services and those who receive services direct from the state (e.g. House of Commons, 2008). Furthermore, civil society actors, including the media, not-for-profit organisations and academics, expressed their dissatisfaction with the decision (McDermont, 2010). An argument put forward in the wake of the decision was that because the government cannot discharge its human rights obligations to "vulnerable" older people in care homes by contracting out of them, the case is essentially about determining who is responsible for their protection (e.g. Carr and Hunter, 2010 p. 316).

The decision on *YL* was effectively reversed by adopting Section 145 of the Health and Social Care Act 2008. Later, Section 73 of the Care Act 2014 was introduced, which enables care home residents to bring claims on the basis of the HRA against private care home providers in British courts. However, this provision applies only to residents whose needs have been assessed or whose care has been arranged or is paid for (in part or in full) by a public authority (Type 1 residents). When caring for Type 1 residents, private care homes are understood to be discharging a public duty; therefore, they can be considered as public authorities under the HRA in cases concerning such residents. Residents who have arranged and pay for their own care (Type 2 residents) cannot use the HRA in legal cases against their independent care home provider. Therefore, the first grade of legal responsibility does not apply to care homes that house Type 2 residents only (see Figure 4.1).

Figure 4.1 Grade 1 Legal obligations under the HRA

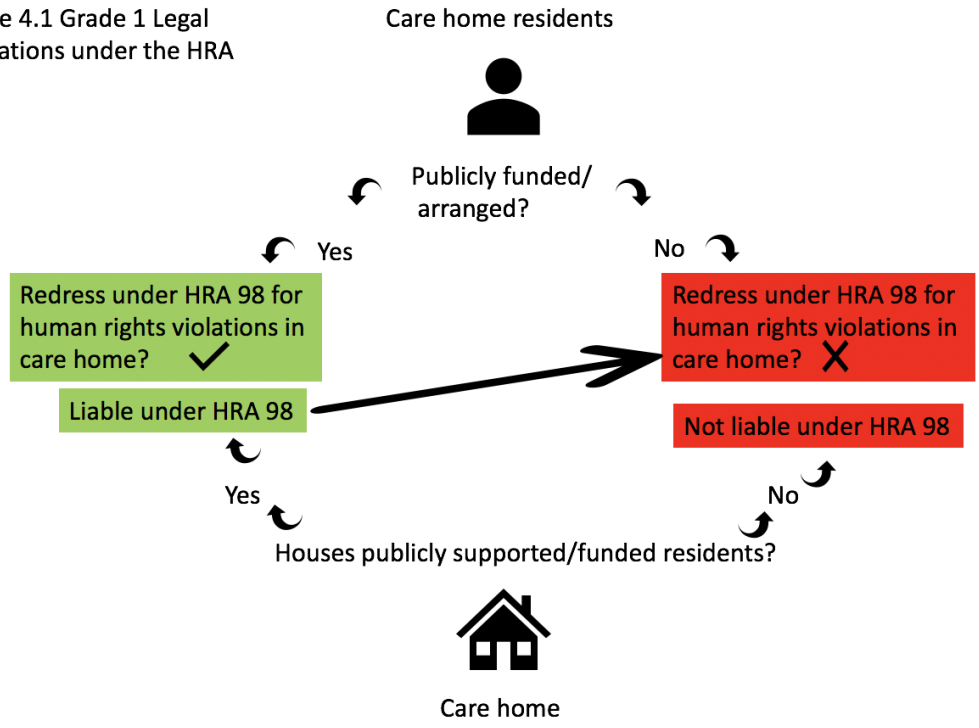


Figure 4.1 Care home providers' Grade 1 legal obligation under the HRA

In parliamentary debates on the Care Bill, which led to the passing of the Care Act 2014, access to protection under the HRA for all care home residents was discussed. However, the government's view was that the HRA did not apply in purely private contractual relationships, such as those between Type 2 residents and their private care homes. Parliament's Joint Committee on Human Rights argued:

> In the Government's view, the HRA is not the appropriate framework for regulating contracts arranged privately, without the State's involvement, between care homes and private individuals or their families… The Government… acknowledges that the ECHR imposes positive obligations on the State to ensure that individuals respect each other's rights, but says that this is not at all the same as placing private individuals and enterprises directly under obligations which were designed to apply to Governments (Joint Committee on Human Rights, 2014).

This highlights some limitations of the trickling-down process of transferring human rights obligations to non-state actors. The result is essentially a discriminatory system that provides uneven access to justice. It may also cause confusion amongst residents and care home providers about whether or not the HRA applies to the care home if they provide services to both types of residents or to one type only. Both types of residents can complain to the Local Government and

Social Care Ombudsman, an independent adjudicator on complaints about adult social care. However, this does not amount to the same level of human rights protection as access to the HRA for legal redress does.

Grade 2: Indirect legal responsibility under CQC regulation and other human rights laws

In 2014, the CQC adopted a human rights approach to regulating all registered providers of care services, including care homes (see Chapter 7). Under this regime, human rights have increasingly infiltrated the CQC's inspection and monitoring mechanisms. The government considered that integrating human rights into the CQC's regulatory power was a way of dealing with the discriminatory access to the HRA for Type 1 and Type 2 residents. This is reflected in the following statement:

> [The Government] points out that "self-funders" of care and support have other avenues [rather than the HRA] of recourse open to them, both legal and non-legal, and that the Health and Social Care Act 2008 strengthened the regulatory regime by ensuring that the regulator [the Care Quality Commission] can inspect all providers to establish whether they are acting in the spirit of the relevant provisions of the ECHR (Joint Committee on Human Rights, 2014).

As is established in Chapter 7, however, self-funded care home residents still cannot raise an HRA claim with the CQC, because the CQC does not investigate individual complaints. Furthermore, there are several limitations to the CQC's human rights approach to regulating. Its regulatory powers and human rights approach do not amount to the same level of human rights protection (at least in theory) for self-funded residents as is given to those who are publicly funded.

The Equality Act, the second major human rights law in England, applies to health and social care services, including care homes (Equality and Human Rights Commission, 2018b p. 8). As this legislation is based on human rights, it places an indirect legal responsibility for human rights on all care homes.

Grade 3: Indirect legal responsibility for human rights through "rights-relevant laws"

Under international and national human rights law, England's government has the duty to protect, respect and promote universal human rights through relevant laws, regulations and policies (see Chapter 2). The HRA further stipulates that all Acts must be compatible with human rights. These include health and safety laws, adult safeguarding laws and consumer law (Dow, 2008 p. 21). Care

homes, and the people managing, working in, living in and visiting them, are in most instances the rightsholders and the duty-holders under such laws.

In 2018, the Competition and Markets Authority published documents to advise care homes for older people about their responsibility to treat residents fairly under consumer law. This advice mentioned residents' and their families' consumer rights, such as the right to receive high-quality care home services (Competition and Markets Authority, 2018a p. 108). The Authority further advised that it may press criminal charges or take action on behalf of individual residents if breaches of consumer law are suspected (Competition and Markets Authority, 2018a p. 17). In some instances, breaches of consumer law could also amount to breaches of human rights under the HRA; therefore, consumer law may provide alternative avenues for legal redress (Dow, 2008). However, most serious cases of abuse committed by individuals in care homes are dealt with under criminal law, such as the Sexual Offences Act 2003.

4.2 Social norms: respecting and promoting human rights

The UNGPs (see Chapter 2) were endorsed by the UK government twice in 2013 and again in 2016 (Foreign and Commonwealth Office, 2016). The government embraced the scope of the UNGPs and with them the "widely accepted social norm of a corporate responsibility to respect human rights" (Ruggie, 2013). Connections have been made between the UNGPs and private care homes (Emmer DA Green, 2017; Care Quality Commission, 2018), which have been argued to fall under the remit of the UNGPs. According to one contribution, the potential positive and negative impacts of institutional long-term care on older people's human rights makes the UNGPs especially relevant for independent care home providers (Emmer DA Green, 2017 p. 359).

In addition, following abuse scandals such as that of Winterbourne View Private Hospital, several policy documents in adult social care indicated a socially accepted norm for all care home providers to promote human rights. For example, a policy paper published by the Department of Health in 2017 contained a commitment from public and private organisations working in adult social care "promoting people's human rights and their equality with others" throughout their work (Department of Health and Social Care, 2017a p. 8). This commitment included care home associations.

An analysis of care home providers' public-facing websites suggested that public acknowledgement of human rights responsibilities is still uncommon; greater emphasis is placed on services, such as a choice of meals, a private hairdresser or garden space (Emmer DA Green, 2017). However, a recent study into the conceptualisation of quality care in England and Australia argued that human rights

are now part of care home providers' understanding of relationship-centred care (Trigg, 2018). This research, together with policy statements, indicates a growing awareness of human rights responsibility amongst private care home providers and managers. However, although normative statements about human rights responsibilities can indicate social expectations and the acknowledgement of these responsibilities, legal accountability or other avenues for seeking redress for human rights violations (see Chapter 2) are essential for effective human rights protection (e.g. Dow, 2008).

4.3 Civil society engagement around human rights and care homes

Civil society organisations have also taken action on human rights in care homes over the past decade. Charities have done research and published practical guidance on how care services can integrate human rights into their provision (e.g. Age UK, 2017; British Institute of Human Rights, 2017). The National Dignity Council, a partnership of organisations in health and social care, has developed the Dignity in Care campaign to "change the culture of care services and place a greater emphasis on improving the quality of care and the experience of citizens using services including … care homes" (National Dignity Council, 2019). It has created the 10-point dignity challenge, which consists of "values and actions that high-quality services that respect people's dignity should follow" (Dignity Council, 2019). The ten points do not mention human rights explicitly, but they refer to the personalisation of care. As argued in Chapter 10, this is largely understood as a human rights approach to care. The ten points also refer to respect for privacy (Dignity Council, 2019). As shown by these examples, civil society activism around human rights in care homes is one component of developing a normative obligation amongst care homes to respect human rights.

4.4 SUMMARY

This chapter defined the human rights framework governing English care homes in the context set out in the previous two chapters. In this framework, care homes have three grades of legal obligations relating to human rights. There is also a social expectation that care homes should protect human rights. These developments point towards a trickling-down process of transferring human rights obligations to care home providers and, to some extent, the people working for them. This chapter also explained that the human rights framework discriminates against residents who do not have access to the HRA if their human rights are violated in care homes. The chapter argued that this is essentially the result of a public/private divide, which the government needs to bridge. The social expectation that care homes should protect human rights may lead to changes in how care homes publicise and even provide services. However, without equal access to legal remedies in the case of human rights violations, the value of such normative statements remains questionable.

In addition, this framework exists alongside the realities of people who are living in, working in or visiting care homes. As mentioned in Chapters 1 and 3, in the widely accepted liberal interpretation of human rights the rightsholder is constructed as an able-bodied, autonomous agent, and the choice and marketisation policies on care services position care home residents in a similar way (O'Rourke, 2015 p. 1010). However, as some studies have suggested, some residents may have difficulties exercising choice (Tanner et. al, 2017). Little is known about access to legal aid and advocacy services that can clarify the framework and help individuals in care homes to navigate the complexities in their needs, pressures and responsibilities.

5 Methodology

Experts in research methodology have criticised human rights scholars for producing unreliable studies that lack methodological rigour and aim to further a human rights activist agenda (e.g. Coomans et al., 2009; Andreassen et al., 2017). It has been argued that some social scientists approach the topic of human rights uncritically and are biased:

> Human rights researchers sometimes cut short their research or approach it selectively because they seek a "constructive" and human rights positive argument to prevail in their research outputs. Consistent with this, human rights research often avoids a critical assessment of certain of its core assumptions and its practical uptake; instead, it is frequently accompanied by a list of recommendations that may serve promotional purposes but do not advance methodologically reliable human rights research (Andreassen et al., 2017 p. 5)

"Reliable" human rights researchers, on the other hand, show methodological awareness. One way to demonstrate such awareness is to set out and justify a project's methodological approach(es) and ethical considerations (Andreassen et al., 2017). Further, the researcher can gain trust by highlighting any normative assumptions, framing their research questions openly and examining counter-arguments and hard cases (McInerney-Lankford, 2017 p. 176). Therefore, this chapter is particularly significant. It provides the space to present and justify the methodological approach adopted in this human rights research and discusses the ethical considerations involved. The concept of human rights has already been defined in the light of different approaches and definitions (see Chapter 1), so this is not discussed further in this chapter.

To summarise, this mixed-methods study explored the potential role of human rights in the context of English care homes from various perspectives. To do so, three research elements were investigated:

1. The CQC's perspective on the potential role of human rights in care homes.
2. The perspectives of people living in, working in and visiting care homes on the potential role of human rights in care homes.
3. Multiple perspectives on the meaning of the right to privacy in care homes, as a case study of one human right.

Separate yet linked research was undertaken for each element. Accordingly, the aim was to answer three sets of research objectives and research questions, each with its own considerations regarding methodology and data-collection methods.

As human rights are both a normative and a legal concept (see the definition in Chapter 1), this research can be considered as socio-legal. It focuses on the sociological enquiry into how people understand and view human rights in care homes. Any legal analysis (for example, conducted in Chapter 4) was for a contextual purposes only. Lawyers' perspectives on the potential role of human rights in care homes were intentionally not directly considered, because this would have made the research too broad. Furthermore, one purpose of this study was to conduct empirical human rights research in and with care homes due to increasing interest amongst human rights professionals and others in care homes for older people.

Thus, Chapter 5 continues by outlining the overarching methodological approach and the research questions. Secondly, it introduces the three study elements and the methods used in each of them. Thirdly, it describes the sampling, recruitment and data-collection methods and the data analysis process. Lastly, it highlights the main ethical considerations of this research. Ethical approval for this study was granted in May 2017 by the Health Research Authority's Social Care Research Ethics Committee (Reference number 17/LO/0818) (see Appendix 5).

5.1 Methodological approach

The thesis took a mixed-methods approach, with a focus on qualitative methods. Qualitative methodologies provide in-depth information about the topic under investigation and seek to identify, interpret and understand attributes and characteristics of the object of enquiry (Landman, 2006). Quantitative methods tend to produce larger data sets showing differences in numbers; they seek to answer research questions statistically (Landman, 2006 pp. 70–72).

Mixed-methods studies, which combine qualitative and quantitative methodologies in one research project, have become more popular in human rights scholarship (Pham and Vinck, 2018 p. 29). Experts in human rights research methodology (e.g. Landman, 2006) have argued that mixed-methods studies can produce more informative, balanced and useful research results than single-method studies. Pham and Vinck (2018, p. 30) explained: "Combining both qualitative and quantitative approaches into a single research inquiry helps to overcome the limitations of a single design. The characteristic arguments are that qualitative methods lack representativeness and quantitative methods lack depth". Research that uses multiple methods to study one phenomenon

can also enhance credibility by triangulating different kinds of data on the same topic (Bowen, 2009).

The primary intention of this study was to engage in depth with the study participants and the materials that were collected in order to uncover perspectives on the potential role of human rights in care homes. Therefore, it was most suited to qualitative research methodologies. However, for elements 1 and 3, a quantitative content analysis of CQC care home inspection reports was undertaken. As discussed in Chapter 7, the CQC has translated its human rights approach to regulating and inspecting care services into its KLOEs. The right to privacy is important here. All CQC inspection reports are publicly available and provide rich data. They can be a valuable source of information on how inspectors choose to communicate with the public about human rights, especially the right to privacy. A quantitative content analysis was suitable for examining the information in these reports.

Mixed-methods studies also raise concerns. Many of these relate to ontological and epistemological considerations and whether quantitative and qualitative research outcomes can be aligned in this regard (Pham and Vinck, 2018). Quantitative research tends to be rooted in positivist schools of thought, whilst qualitative research is often constructivist. However, Pham and Vinck (2018) maintained that such epistemological considerations must not be taken so seriously that they hinder combining the two methods for a robust research output. That is, the value of mixed-methods research outweighs the ontological and epistemological considerations: “The emergence of mixed methods research is less philosophical, but rather emerged from the need to provide a practical, in-depth, but quantifiable understanding of social issues with direct practical outcomes in shaping programs and policies” (Pham and Vinck, 2018 p. 30).

In human rights research, especially when studying the philosophical foundations of human rights, epistemological considerations are important. They direct the way a researcher approaches the research topic. Given that the concept of human rights had to be defined for the purposes of this research, ontology and epistemology had to be considered to a certain degree. This research aligns most closely with a social constructivist/interpretive way of thinking, which allowed the researcher to listen and take seriously different perspectives on the role of human rights in care homes. This is compatible with the quantitative research element, as the methods ultimately served the same purpose: to capture perspectives.

Another criticism of mixed-methods studies is that one method may be privileged over another (White et al., 2014). This can influence how researchers present data, which can lead to contradicting results. Valuing methodologies – and the data gathered – as equally worthy of

reporting helps to counter this criticism. Triangulating the qualitative and quantitative data produces results in which the types of data complement rather than contradict each other, and highlights their equal value (Ritchie and Lewis, 2014). This study is mostly qualitative, but where simple quantitative methods were used, this data complements the qualitative data. In element 3, the interview participants were asked to give their personal perspectives on what the right to privacy means in care homes. This was complemented by data on the CQC inspectors' definitions of the right to privacy in their inspection reports, yielding indicative results that allow a integrative interpretation of the qualitative data. Of course, there are limitations to these results. The CQC reports selected cannot be considered as a representative sample, and it is not the intention of this thesis to produce generalisable results (see Section 13.2).

5.2 Patient and public involvement

The involvement of older people and service users was sought at various phases of this study, including the conception and design stages. For example, the study, its research questions and interview methods were presented to the Social Care Workforce Research Unit's user and carer advisory group in January 2016. This was important for the study because no pilot interviews were undertaken. This was due to the need to receive ethical approval and the limited time and resources available to the participants. The members of the advisory group, who are service users and family carers, provided some valuable feedback. These were incorporated into this study's design. For example, one technique in the qualitative interviews involved using a set of images to aid communication about abstract concepts. To make the technique useable with one person, the members of the advisory group recommended presenting participants with only a few of the images.

Throughout the research process, the study was presented at various conferences and seminars (see Appendix 3). This created opportunities for critical discussions around the research and informed professionals and members of the public about it. One example was a presentation at the CQC's internal human rights and equality conference in February 2018, which was attended by around 100 people. Through this, inspectors and CQC staff who attended were informed about this study involving the CQC.

5.3 Research objectives and research questions

There were three elements to this study, each with its own research objectives and research questions under an overall study aim and objective. Table 5.1 provides an overview of the structure.

Table 5.1 Overview of the PhD research elements

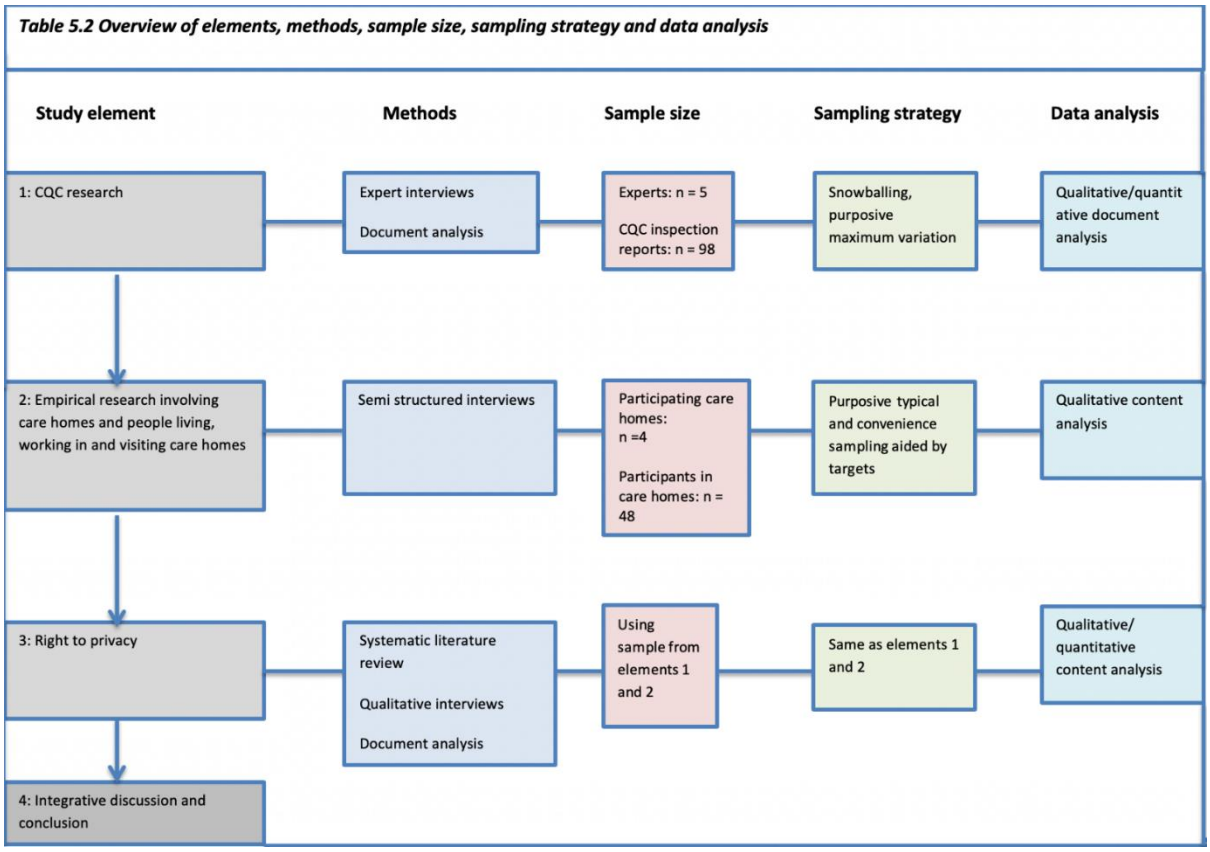
Study aims			
1. To contribute towards a mutual understanding on the potential role for human rights in the context of care homes in theory and in practice. 2. To contribute towards a mutual understanding on good practice for respecting care home residents' right to privacy. 3. To contribute to the body of multi-methodological human rights research involving care home residents, care home managers, care workers and relatives of residents and the Care Quality Commission.			
Objectives and research question for each element			
Element	**Methods**	**Objectives**	**Research questions**
Element 1: CQC research	Qualitative interviews, document analysis	To explore the CQC's perspective on the potential role for human rights in care homes through critically engaging with a range of CQC documents and experts.	What is the background to the CQC's human rights approach? What is the CQC's explanation of their human rights approach to regulation and inspection? What is the role and purpose of their human rights approach, according to it?
Element 2: Care home research	Qualitative interviews	To explore perspectives on the potential role of human rights for people living, working in and visiting care homes.	How do people visiting, living and working in care homes understand the concept of human rights? What role do participants think human rights play for care homes? What role do participants think human rights *could* play for care homes?
Element 3: Right to privacy	Systematically conducted literature review Qualitative (interviews, document analysis) Quantitative (analysis of CQC reports)	To explore the practical implications of the human right to privacy in a care home context from multiple perspectives	What is the evidence for good practice in protecting care home residents' right to privacy? What, according to study participants, is necessary to protect the right to privacy in a care home setting?

			What, according to CQC inspection reports and other relevant documents, is good and bad privacy practice in care homes?

5.4 Methods

The study involved data from documents and interviews with individuals in addition to a qualitative and quantitative content analysis. The data gathered for elements 1 and 2 of the study also served element 3. In addition, element 3 included a systematically constructed literature review of the evidence for good practice on protecting care home residents' right to privacy. Table 5.2 shows each type of data collected under each element.

Table 5.2 Overview of study's elements, sampling strategy and method for data analysis



The following section introduces the methods used in the qualitative interviews and document analysis.

5.4.1 Qualitative interviews

This research included semi-structured interviews with CQC experts and people living in, working in and visiting care homes. Interviews in qualitative research provide an opportunity to engage in

depth with the research participants and extract their perspectives and experiences of the research question. Interviews can be open, semi-structured or structured. Structured interviews are preferred by quantitative researchers. Open interviews do not rely on pre-defined questions or questionnaires, and they are particularly useful for such methods as grounded theory. Semi-structured interviews, however, follow a broadly defined interview guide, which means the researcher asks the same kinds of questions to each participant.

Care homes are unique, complex and heterogeneous environments to research, and the needs and well-being of residents and staff must be considered (Luff et al., 2015 p. 2). The researcher must be aware of and accommodate pressures on staff and any physical or cognitive impairments that participants have. Other qualitative data-collection methods, such as focus groups, were considered, but these were rejected for several reasons. Conducting focus groups across four care homes, for example, would have raised ethical questions; in particular, about taking up the time of several care workers whilst they were on duty and discussing a potentially sensitive topic in a group setting. Semi-structured interviews were chosen because they would allow enough flexibility to accommodate individual perspectives and circumstances, whilst providing enough structure for a smooth analysis of the transcribed interviews afterwards. Furthermore, preparing questions before the interviews made it possible to seek stakeholder engagement.

In practice, one topic guide was produced for each type of participant (care home managers, residents, relatives and care workers). The guides had a common set of research questions at their core, but took into account the participants' different roles in the care homes.

In interviews, techniques may be used to drive participants' engagement and reflection (Luff et al., 2011; Moriarty, 2011). Such techniques may also support participants to identify perspectives and emotions without intruding too much on their personal experiences. It was important to consider these due to the sensitive nature of the study, which could cause distress or other negative feelings in the participants. Therefore, the semi-structured interviews were accompanied by a toolbox of interviewing techniques. Two of these were photo-elicitation and emotional touchpoints (see below for an explanation). They were adapted from the My Home Life (MHL) Scotland and England Initiative (Owen et al., 2012) after obtaining permission from the programme co-ordinators. MHL has been bridging academic research and improvements in care practice in care homes for more than ten years (Barrie et al., 2016). They have been developed to engage care workers, residents and other individuals in care homes in order to collect their perspectives on topics related to care and well-being (Sharp et al., 2017). They were developed with stakeholders and have been validated and

evaluated for effectiveness in care home settings (Sharp et al., 2017). The following techniques were part of the toolbox.

Photo-elicitation

In this method, researchers use images to support participants to communicate their opinions and emotions around abstract concepts. Images can invoke deeper elements of human consciousness and stimulate a stronger cognitive response than words alone (Harper, 2002). Furthermore, they can help to build trust and a relationship between the researcher and the participant, especially if the researcher follows the same procedure as the participant. First, the researcher asks the participant a question and invites them to choose the image from a set of photographs that best represents their response to the question. The participant then answers the question using the image to support them, and the researcher does the same with their own choice of image.

Emotional touchpoints

Using emotional touchpoints can help researchers learn about participants' lived experiences in care home settings. A "touchpoint" is an experience or topic (e.g. being heard, the care home environment, my space) that provides a basis for dialogue between the participant and the researcher. Usually, touchpoints are thought of and chosen with the participants. In this study, the touchpoints were prepared before the interviews (e.g. human rights, my space, privacy in the care home environment) in accordance with the research questions and topic guides. For each touchpoint, the participants were given a set of positive and negative emotion words to choose from according to which words adequately reflected their feelings on the touchpoint. The participants then talked about the touchpoint using the chosen emotion words (Dewar et al., 2010). This technique can help the researcher and the participant to explore deeper meanings of experiences, which generates richer data on the topics.

Storytelling

Storytelling is a narrative approach to collecting qualitative data. It centres on the participant's experiences by giving them the space to think about and narrate a story from personal experience. Used in qualitative interviews, storytelling has several advantages. It gives the participant the chance to make sense of complex, interconnected situations by linking them to their personal experiences (Sharp et al., 2017). It captures people's experiences by tapping into various dimensions of their knowledge, and it helps to build a relationship between the researcher and the participant (Dewar and Nolan, 2013; Sharp et al., 2017). It also provides data on the participant's perspective on the research topic. Gathering information and narratives from participants helps researchers to explore how they interpret the world and their place in it, which can often be difficult to assess in other

ways (Dewar and Nolan, 2013). It is a generative tool for co-design that captures participants' self-expression (Sanders, 2000; Wilkins, 2004). Dewar and Nolan (2013), for example, used the technique with older residents of care homes to develop a model for "compassionate relationship centred care in older people care settings".

In addition to the semi-structured interviews in care homes, exploratory interviews with experts were undertaken. Researchers usually use exploratory expert interviews at the outset of an academic project to identify relevant anchor points and issues for future research. An "expert" for exploratory interviews is someone who has specialised knowledge of the topic of interest through action and experience (Bogner and Menz, 2009 p. 47) For the purposes of this study, semi-structured interviews with CQC inspectors were conducted before starting desk research on the documents. This provided opportunities to ask about the history and purpose of the CQC's human rights approach to inspecting and regulating services, including care homes. Furthermore, it enabled the researcher to enquire about the role of human rights in the current inspection mechanisms and ask which documents and reports set out the approach. The interviews provided an evaluative perspective on the uses and challenges of such an approach for care homes and inspectors. Both types of interviews – with experts and with care home participants – included questions about the subjective meaning of human rights and the right to privacy in care homes.

5.4.2 Document analysis

Document analysis is "a systematic procedure for reviewing or evaluating documents – both printed and electronic material" (Bowen, 2009 p. 27). It "requires that data be examined and interpreted in order to elicit meaning, gain understanding, and develop empirical knowledge" (Bowen, 2009 p. 27).

Documents are social constructs, free from a researcher's intervention, that contain text and sometimes images. Document analysis may include multiple types of document, such as background papers, policy publications, reports and website text. The systematic procedure involves sampling documents according to pre-defined research questions, finding and storing them, coding and analysing the information they contain and interpreting them using appropriate analytical methods (Labuschagne, 2003).

Document analysis often complements other research methods, including qualitative interviews. It is especially valuable for multi-methodological studies that follow a scheme of triangulation and integrate different types of data (Bowen, 2009). Therefore, document analysis was used for research elements 1 and 3 of this study in order to complement the interviews with CQC experts and the participants' perspectives on the right to privacy in care homes.

There exists a concern regarding research methods that rely on documents (O'Leary, 2014). Firstly, the authors, creators and researchers may have been biased when producing, collecting and analysing the documents. It was important to consider this, as the CQC experts who had created the documents on the organisation's human rights approach were strong advocates for the approach. This issue can be tackled by evaluating the original purpose of the documents and their target audience, and discussing any concerns in the research study. Researchers should also regularly re-evaluate their objectivity whilst collecting and analysing the data (Bowen, 2009).

Secondly, there are concerns about "unwitting" evidence or latent content. This refers to the style, tone, agenda, facts or opinions contained in the documents (O'Leary, 2014). Therefore, the documents must be analysed critically and such latent content must be noted. This can produce more valuable and reliable knowledge than simply re-stating what is written in the document. To tackle these concerns, an analysis of the context in which the CQC produced the documents used in this study is provided in Chapter 7, section 7.2..

5.5 Sampling, recruitment and data collection

This section explains the sampling procedure, the recruitment of study participants and the data-collection process for research elements 1 and 2. These also served element 3.

5.5.1 Element 1: CQC research

5.5.1a Exploratory expert interviews

Five CQC experts were interviewed for this study. This target was set at the outset of the research. To qualify as experts for this study, participants had to be employed by the CQC as care home inspectors or in another capacity inside the organisation.

At the planning stage, it was assumed that negotiating access to CQC inspectors and other staff to interview could be difficult. Therefore, a purposeful snowballing strategy was used to identify potential participants. Purposive sampling is a strategy for choosing units for investigation (or participants) that relies on the researcher's judgement. It is commonly used in qualitative studies that focus on the characteristics of a particular phenomenon. Snowball sampling is also referred to as chain referral sampling. Potential participants are identified through referrals made by people who share (or know others who share) the characteristics needed for the study's sample (Biernacki and Waldorf, 1981).

This strategy was well suited for this phase of the study. First, the CQC website was scanned to find the most recent policy paper outlining the organisation's human rights approach to regulation and inspecting services. The researcher then called the CQC's general enquiry line and asked to be

referred to individuals in the organisation who had been involved in drawing up that policy paper. The request was passed to the relevant expert in the CQC, who contacted the researcher by e-mail. This established a first contact with the CQC. In a series of phone calls and subsequent face-to-face meetings, the researcher introduced the purpose of the study and recruited two CQC experts. These contacts offered to advertise the study internally. Through this process, further potential participants contacted the researcher and another three inspectors were recruited. Relevant external experts did not agree to participate because of resource constraints. The researcher did participate in a CQC human rights training programme conducted by the British Institute of Human Rights. However, the training handbook, which underpins the programme, was not publicly available; therefore, it was excluded from the document analysis.

5.5.1.b Documents

Four document types were considered for inclusion under this element:

Type 1: Publicly available CQC papers outlining the organisation's human rights approach to regulating and inspecting social care since 2014.

Type 2: CQC guidance and regulation documents for care home providers, such as KLOEs and relevant regulations, including Regulation 10 of the Health and Social Care Act 2008 (regulated activities) Regulations 2014, "Dignity and Respect" (CQC, 2018d).

Type 3: CQC care home inspection reports (n=104).

Type 4: Other CQC documents that could provide relevant information.

For types 1, 2 and 4 there was no sampling strategy *per se*. However, inclusion and exclusion criteria were defined to ensure that the documents were relevant. First, the documents had to be published from 2009 onwards, when the CQC was established. Types 2 and 4 were scanned for the following keywords: human/rights, privacy, dignity, respect, choice, control, and person-centred care. Documents containing one or more of these keywords were included if they could provide information about the CQC's human rights approach.

For type 3 (the inspection reports) a sampling strategy was used. The CQC website makes available thousands of inspection reports on registered care homes across England. These rate the care home inspected as "outstanding", "good", "requires improvement" or "inadequate". The following inclusion criteria were defined for these reports:

- Reports had to be published less than one year before the date the data collection began.

- Reports had to be on care homes exclusively for people aged over 65 years.
- Reports had to be on registered residential care homes in England.
- Reports had to be publicly available on the CQC website.

A purposive maximum variation strategy was followed for collecting reports. This strategy aims to cover as many perspectives on one phenomenon as possible. This can help researchers to discover common themes. Therefore, the strategy was suitable for identifying the care practices associated with the right to privacy under the CQC's human rights approach. The inclusion criteria were important for this purpose, because they defined the remit of reports to define the sample from. However, this thesis does not claim that the findings are representative of all inspection reports. Due to time and resource constraints, the research was limited to a sample of 104 reports. This provided a snapshot of maximum variation in different types of reports on registered care homes for older people over a 12-month period. Table 5.3 summarises the inclusion and exclusion criteria for this stage of the research.

Table 5.3 CQC research: inclusion/exclusion criteria

Sample	**Inclusion criteria**
Experts	Employed by the CQC either as inspector or in any other capacity. Individuals external to the CQC but with knowledge about the CQC's human rights approach to inspecting care homes.
Inspection reports (n=96)	At least: 2 reports – from category "outstanding" 2 reports – from category "good" 2 reports – from category "requires improvement" 2 report – from category "inadequate" all per month for a twelve months period. published less than one year before the date the data collection began. on care homes exclusively for people aged over 65 years. registered residential care homes in England. of "nursing homes"or care homes with nursing and those with dual registration

Data collection

The data-collection process for element 1 began in June 2017 with the expert interviews. All the interviews were conducted over the phone, because the participants were located in different parts

of the country and had limited time available. One expert was interviewed twice: once before the data analysis and once afterwards. The reasons are explained in Section 5.6.

Before the interviews, the expert participants were sent a project information sheet and a consent form, which they signed and returned by e-mail. Broad questions guided the researcher in these interviews, but overall they were open and unstructured. This allowed the experts to guide the researcher on what knowledge they believed was relevant. The interviews lasted for between 30 minutes and 2 hours and were recorded with the participants' consent. One of the interviews failed to record, partly due to a fault with the equipment. The researcher took notes immediately after the interview, but no quotations from this particular part are included in this thesis.

The interviews were transcribed using an intelligent verbatim method. The same method was used for the interviews with the care home participants. Following this method, the transcriber edits out any sounds or pauses in a bid to capture *what* was said rather than *how* it was said (Poland, 1995). The focus is on the content of the interview rather than fillers and noises. Consequently, non-verbal cues, which could have provided an insight into participants' perspectives on the research topic, were not captured. There are challenges associated with transcribing interviews, such as the content quality in relation to the representativeness of what was said on the recording (Poland, 1995). However, for the researcher to analyse the data with other data sources, transcription was necessary. Care was taken to ensure the quality of the transcription. As explained above, various interview techniques were used to support the care home participants to verbalise their emotions and perspectives so that they could be reproduced in analysable documents.

The data collection for type 1, 2 and 4 documents began alongside the expert interviews, using the CQC's public website (www.cqc.co.uk) and following the guidance provided by the expert interviewees. First, type 1 documents were collected and references sections were scanned to identify type 2 and type 4 documents. Documents were also identified by entering the following keywords into the search function on the CQC website: human/rights, privacy, dignity, respect, choice, control, person-centred care. Once potentially relevant documents of types 1, 2 and 4 had been identified, they were downloaded (if permitted) and stored in a file for data analysis. An overview of these documents in provided in Chapter 7, Section 7.2.2.

The collection of type 3 documents – the CQC reports – began in April 2018. The date was recorded and 12 months were counted back. The CQC website has a search function for care home inspection reports. The remit of this study's search was defined by year, service type (i.e. residential care homes for people aged 65 years and older) and rating ("outstanding", "good", "requires improvement", "inadequate"). A spreadsheet with a list of inspection reports that met these criteria

was downloaded. From this list, the aim was to collect two reports for each rating in each month during the 12-month period (n = 24 per rating category). However, some months did not contain two reports of the same rating. This was compensated for by choosing another report from a month that had more than two reports with the same rating. Some reports were too short, with insufficient text to analyse. To compensate, another eight reports were identified and downloaded. In total, 104 inspection reports were downloaded that fit the inclusion criteria. These were saved in a designated file for data analysis. An overview of the inspection reports by rating is provided in Chapter 7.

5.5.2 Element 2: care home research

The sampling and recruitment for element 2 was done in two stages. First, care homes had to be recruited; then, participants in those care homes could be recruited. The planned sample size was four care homes and 48 people working in, living in or visiting the care homes (care home managers n=4, care workers n=20, residents n=12, and relatives n=12). This section describes the sampling strategies and the inclusion and exclusion criteria that were used to recruit care homes and participants.

5.5.2.a Participating care homes

For element 2, four care homes had to be identified and agree to participate in the research (i.e. by allowing the researcher to visit and to recruit interview participants). A purposive typical sampling strategy was used. Here, the researcher chooses samples that are normal (or "typical") for the unit under study. This does not mean that the sample is representative of the entire sector or group of people. However, typical case sampling allows researchers to compare or combine the findings in a sample. Thus, the findings may be indicative of other, similar samples. For care home research, it can be helpful to select cases in co-operation with key informants, such as experienced care home researchers, who have knowledge about what is typical in the sector (Patton, 2002 p. 236). The aim was to recruit medium-sized care homes that housed between 20 and 50 residents and had a CQC rating of "good" or "requires improvement". Care homes registered as nursing homes were excluded. Those with a CQC rating of "inadequate" were also excluded, because including them could have added ethical challenges to the research.

Care homes that fitted the inclusion criteria were identified using the CQC website. The researcher telephoned them to explore their interest in participating. However, this strategy did not work, as none of the managers were interested. The researcher was then invited to a meeting of care home managers organised by MHL England and held at City University of London in May 2017, which provided the opportunity to tell the attendees about this research. Three of the four participating care homes were recruited through this meeting. The fourth was recruited after another meeting

held later in the same year. After initial face-to-face talks, the care home managers were sent the project information sheet. Then the researcher visited each care home to answer any questions and discuss the details, including the procedure for recruiting participants in the care home. The managers signed a consent form for participating care homes.

5.5.2.b Participants in the care home

A convenience sampling technique was used to recruit participants from the participating care homes. Under this strategy, participants were chosen because of "convenience of accessibility". Convenience of accessibility was defined with the care home managers and considered inclusionary targets. In convenience sampling, researchers select categories and choose participants accordingly as far as possible. In this research, the aim was to ensure that the sample reflected as closely as possible the diversity and key characteristics of the people living in, working in and visiting care homes.

All participating residents had to be at least 65 years old, and the aim was to include some who were 85 or older. Regarding ethnic minority groups, the 2011 census (Centre for Policy and Ageing, 2013) showed that most of Britain's Black, Asian and minority ethnic (BAME) populations were concentrated in London. This may be mirrored in care home populations (Centre for Policy and Ageing, 2013 p. 3). The researcher aimed to include residents with a BAME background, but this was difficult in the participating care homes due to their location: three were located in rural southern England and one was located in a town in the south of England. No care home in Greater London could be recruited due to capacity constraints in the care homes.

Residents who lacked the capacity to consent to participate in the research (i.e. people with severe dementia or other severe cognitive impairments) were excluded from this study. The decision to exclude a group on the basis of their impairment was counter-intuitive and, as a human rights researcher, it was not an easy decision to make. However, this research could be carried out with equal effectiveness if confined to participants with the capacity to consent. Therefore, under the MCA 2005, it was not necessary to include adults lacking capacity in the study (MCA 2005, s.31(4)). Furthermore, conducting research with people who have dementia or other cognitive impairments may require a different methodological approach from research with people who do not have these impairments. This may be especially true in human rights research, which can be upsetting for participants and involves abstract concepts. Testing and providing a toolkit for interviewing people with dementia was beyond the remit of practicability for this research. Furthermore, in practice, the care home managers of the participating care homes did not introduce the researcher to residents

with dementia or other cognitive impairments; therefore, no one was actively excluded from the research for that reason.

People who could not communicate in English on an appropriate level were also excluded. This was due to the lack of financial means to pay an interpreter. In practice, however, the researcher did not have to make this decision, as all the potential participants spoke English.

The adult social care workforce in Britain has the following key characteristics (SkillsforCare, 2018c):

- 82% are female.
- 83% hold British citizenship, 10% are from non-European countries and 8% are from countries in the EU.
- People with a BAME background make up 21% of the workforce.

The aim was to have a sample of participants that reflected these characteristics, including at least some staff, relatives and managers with a BAME background. The aim was also to include people with a LGBTQ+ (lesbian, gay, bisexual, transsexual, questioning or other) background, and relatives and staff with disabilities. However, for data protection reasons, the participants were not asked to disclose this information. Rather, they could share it with the researcher if they wished to. Other inclusion requirements were that participants must be a registered care home manager, a care worker who is engaged in social care, or a relative of a care home resident who was living in one of the participating care homes. Nurses employed by the NHS, and other NHS employees, were excluded from the study.

Table 5.4 provides an overview of the final inclusion and exclusion criteria for participants in element 2.

Table 5.4 CQC research: Overview of inclusion/exclusion criteria

Participant group	Inclusion criteria	Exclusion criteria
Care homes	Care homes (residential) offering long-term accommodation and personal care; Registered, regulated and inspected by the CQC; Independent, i.e. private or voluntary sector run.	Caring for people under 65 years of age only; Specialised on one type of service e.g. dementia care only; Managed by a local authority i.e. state-owned and run; Nursing homes, dual registration; Having a most recent CQC inspection assessment of "inadequate".
Care home managers	Registered manager of a care home.	
Care home residents	Individuals aged 65 years and over; Individuals living in the care home permanently.	Individuals lacking capacity to consent to participate in the study; Participants not able to communicate in English to the necessary level.
Care workers	Care workers directly engaged in the everyday personal care of care home residents.	Healthcare workers funded by the NHS; Participants not able to communicate in English to an acceptable level.
Relatives of care home residents	Individuals who have family members living inside the participating care homes (but not necessarily those who participated in the research).	Participants unable to communicate in English to an acceptable level.

To recruit participants, managers of participating care homes informed their staff, residents and families about the background of this study and its rationale. Over 11 months, the researcher visited care homes several times to recruit participants and conduct interviews. During these visits, which were arranged beforehand to minimise disruption, the managers introduced the researcher to residents whom they thought would be happy and able to participate in the research. After the initial meeting phase, potential participants were informed about the research and given an information sheet (if they had not already received one from their care home manager). Most residents decided straight away whether they were happy to participate.

Care workers and relatives were also recruited during field visits. To do so, the researcher often approached staff or relatives in communal areas of the care home and informed them briefly about the research. The study was advertised on internal noticeboards with the consent of the manager. Individuals who were interested were handed an information sheet. Staff and relatives then told the researcher on the same day whether or not they were happy to participate. In some cases, the care home managers introduced the researcher to members of staff. The researcher asked these staff members in private whether they indeed wished to participate. The ethical considerations around care home managers acting as gatekeepers are discussed in Section 5.7.

5.5.2.c Data collection

All interviews with care home managers, residents, relatives and members of staff took place in the participating care homes. The care home managers usually allocated a private room with a door that could be shut. The interviews were conducted in these private rooms unless residents or relatives wished to be interviewed in their bedrooms. Before commencing the interviews, the purposes of the study and the consent form were explained, and all the participants gave their consent. In the rare cases in which a participant was not able to sign the consent form, their verbal consent was recorded without disclosing their personal details on the recording.

The interviews lasted for between 15 minutes and 45 minutes, with an average length of 30 minutes. The toolbox of interviewing techniques was used, as described above. For the photo-elicitation technique, 20 images with motifs were laid out on a table (see Chapter 10, images 10.1, 10.2, 10.3 and 10.4 for examples). The researcher began each interview by asking the participants the question “What do human rights means to you?” and inviting them to choose the image that best represented their answer. In most cases, this provided access to a rather abstract topic; however, it is recognised that the choice of images might have prompted answers that influenced some of the findings. This is discussed further in Chapter 10. The researcher asked the participants

how they would like to conduct the conversation; in line with their responses, emotional touchpoints were used in around half of the interviews. A few participants chose not to use the images and preferred a conversation without any tools, but storytelling was part of every interview.

The interviews were audio-recorded with the participants' consent. Two participants did not wish to be recorded, so the researcher took notes throughout the interviews. Around 13 hours of recordings were transcribed, mostly by the researcher but partly by a specialist transcription service. The method used for the expert interviews was followed at this stage as well. The recordings were deleted after transcription, names mentioned in the interviews were anonymised, and the transcripts were stored in a safe place on the researcher's desktop.

5.6 Data analysis: qualitative and quantitative content analysis

To analyse the data, interpretative qualitative and quantitative content analysis techniques were used. The analysis was aided by MaxQDA analysis software, into which documents can be uploaded and coded according to the chosen analysis process. Content analysis focuses on the data analysis rather than the data collection (Schreier, 2012 p. 31). It has been defined as follows:

> Content analysis refers to a family of procedures for the systematic, replicable analysis of text. In essence it involves the classification of parts of text through the application of a structured, systematic coding scheme from which conclusions can be drawn about the message content. (Rose et al., 2015 p. 1)

The main difference between qualitative and quantitative content analysis lies in the coding process. In quantitative content analysis, the focus is on the statistical description of manifest document content; in qualitative content analysis, the researcher is more interested in describing differences and emerging themes in texts (Schreier, 2012 p. 13). Researchers may use content analysis on different kinds of documents, from interview transcripts to an organisation's public records, such as policy reports. Other document types include those classed as "physical evidence", such as training materials, texts on websites, posters, flyers and handbooks (O'Leary, 2014; Rose et al., 2015). The value of content analysis lies in its ability to integrate different kinds of data to find answers to complex or simple research questions

Qualitative content analysis must not be confused with critical discourse analysis: a qualitative research method in its own right, which critically engages with linguistic material to find patterns of power in discourse (Schreier, 2012). Frequently, studies adopting critical discourse analysis are theory-driven and may be "activist" in nature, aiming to highlight social and political power constructs through language and action (Landman, 2006 p. 61). Landman (2006 p. 61) summarised

the academic purpose of critical discourse analysis as follows: “The goal of such analysis is to produce new interpretations about specific objects of investigation … by problematizing existing accounts and articulating alternative interpretations.” This type of analysis is valuable for uncovering the language, symbols and actions used by elites to construct social orders and for offering alternative, theory-based and author-led interpretations of the subject under investigation.

In qualitative content analysis, however, the focus is on understanding the “nature and meaning of the social world that is constructed by the subject population under investigation” (Landman, 2006 p. 59). Studies using this method often seek to contribute to policy and practice by describing and interpreting the material that has been collected from the study participants. Such studies are less reliant on theory than those that use critical discourse analysis, and they focus on the voices of the study participants rather than on that of the author. Such thick-description studies using qualitative content analysis have been criticised for being “atheoretical”, “too descriptive” and offering limited social scientific value (Lijphart, 1971; Landman, 2006 p. 59).

It was necessary to decide whether to use qualitative content analysis or critical discourse analysis (or both) for the purposes of this thesis. This decision had to be made at the beginning of the research process, because the direction would have bearings on the research question and study design. Qualitative content analysis was chosen because the review of the academic literature revealed that there was a lack of human rights research involving people who live in, work in and visit care homes. It is the researcher’s standpoint that for human rights to be valuable and applied in practice in care homes for older people, it is important to hear the voices of the relevant stakeholders in the debate. Although the study can be criticised for being too descriptive, especially in Chapters 7 to 9 and Chapter 11, the researcher intended to provide space for the participants’ contributions to the topic rather than offering her own perspective. The researcher aimed to interpret the findings in the context of the wider social, legal and policy framework rather than from a theory-led point of view.

There are some contentious issues in qualitative content analysis. One of these is the reliability of the coding and the subsequent interpretation of the data. The reliability of the coding is highly dependent on how consistently the data is interpreted during the coding process (Schreier, 2012 p. 167). This challenge can be overcome by having more than one coder code the data and by using a comparison process to increase consistency and, thus, reliability. In this research, there was only one coder; however, to increase reliability the researcher re-read the data and tested the codes several times over three months.

There is an important technical difference between qualitative content analysis and critical discourse analysis. In the former, the focus is on describing what the material says; in the latter, the researcher also looks for what is not included in the material (Schreier, 2012). At the same time, considering the "unwitting" evidence provided by the documents is important for producing reliable results. In this study, the unwitting evidence in the sample of CQC documents was considered and forms part of the wider analysis of the organisational development taking place in the CQC (see Chapter 7, section 7.2). To verify the unwitting evidence that the researcher had interpreted from the CQC documents, one expert participant was interviewed a second time to ask for feedback.

Content analysis involves a systematic sequence of steps. These are as follows: (1) build a data-driven and/or concept-driven coding framework using a sample of the data; (2) divide the material into units of coding; (3) test the coding framework; (4) adjust and revise the framework; and (5) code all the material using the revised framework. Coding frameworks consist of dimensions, categories and sub-categories in accordance with the complexity of the data. The results must be interpreted and presented in a study; for example, by producing a typology, as is done in this thesis. A typology is an overview of group characteristics, which can be compared with those of other groups relating to a common denominator. A grouping process is used to construct the typology, and that process can emerge from a qualitative analysis coding framework (Schreier, 2012 p. 229). The grouping process can help to summarise the results, include rich descriptions and include individual case studies.

To clarify, quantitative content analysis was used in elements 1 and 3 of this thesis. For element 1, the CQC inspection reports were scanned to quantify the use of human rights language in the reports. This provided some indication of whether and how the inspectors chose to communicate with the wider public about human rights. The reports were searched for keywords and the number of reports containing these keywords were counted. The results are not intended to be generalisable.

Under element 3, the inspection reports were scanned to draw out common practice points related to privacy and to see whether the inspectors commonly choose to communicate with the wider public about privacy. The inspection reports do not provide insights into the process that takes place before an inspection or whether the inspectors use human rights language during that process. Such research was beyond the scope of this thesis. Thus, two separate coding processes took place, following the steps described above.

The first coding process included four dimensions: "no mention of human rights/rights", "mention of human rights", "mention of rights", and "mention of 'FREDA' or any of the principles". Three of the

dimensions had several data-driven categories that captured, for example, the specific rights that the inspectors frequently referred to (e.g. the right to dignity or rights under the MCA 2005). The inspection reports were then scanned using keywords and variations. The second coding process followed the same steps, using a sample of the reports to build a coding framework that would capture the right to privacy and privacy in the inspection reports. The dimensions and categories were then quantified, as reported in Chapters 7 and 10. The limitations of this approach are explained in Chapter 13.

Regarding the qualitative elements of this research, six different coding frameworks were developed initially: one for each participant group and one for the CQC documents. This was due to the differences in the research questions for elements 1 and 2, the use of documents for element 1, and the differences in the interview guides. For each coding framework, the same systematic steps were followed. The initial phase involved building a data-driven coding frame, dividing the data into units and segments of analysis, testing the framework using more of the data, adjusting the framework, and then coding the rest of the interviews according to their group. As reported in Chapters 7 to 9, several dimensions, categories and sub-categories emerged. These are reflected in the headings under each participant group in those chapters. After the coding had been completed across the data, the interpretation process began. The typology of perspectives and the right to privacy in care homes model emerged from integrating the analytical results.

To construct typologies, a further methodological step is necessary beyond the content analysis (Schreier, 2012 p. 49). To produce the typology, the researcher followed Kluge's (2000) guidance on the empirical construction of types and typologies. This involved developing "analysing dimensions" (i.e. the four main approaches to the potential role of human rights in care homes, as presented in Chapter 10), grouping cases (i.e. participants), and analysing any empirical regularities according to the dimensions (see Section 10.2). The typology was then placed in a wider analysis of contextual factors for conducting human rights research (see Section 10.1).

5.7 Ethical considerations and research governance

This research involved the empirical study of human rights. Most empirical human rights research is "sensitive research", because it can entail potentially harmful consequences for participants and researchers (Landman, 2006). Thus, ethical conduct throughout the research process had to be ensured, and the researcher had to be aware of any potential sources of harm. As stated in the Department of Health's Research Governance Framework for Health and Social Care, "The dignity, rights, safety and well-being of participants must be the primary consideration in any research study" (Department of Health, 2005 p. 7). This is particularly important when interviewing

individuals living in, working in and visiting care homes. This section describes the ethical issues that were relevant to this research and the strategies that were used to address them.

5.7.1 Sensitive information

Care and human rights are both sensitive topics. Living in, working in and visiting a care home have all been identified as potentially stressful and emotionally charged experiences (Luff et al., 2007). Talking about human rights in this setting might have encouraged participants to recount distressing experiences, made participants feel exposed and vulnerable, or encouraged feelings of anger or grief. To handle this effectively, the researcher checked for signs of distress, anger or discomfort and reminded participants of their right to withdraw from the study. Care was taken to provide detailed information about the project that was tailored to the needs of participants and to reassure them that their responses would be kept confidential. This was intended to minimise distress and encourage feelings of ease with and trust in the researcher. The researcher underwent an enhanced Disclosure and Barring Service (DBS) check to assure the care homes and participants of her character (GOV, 2019a). Furthermore, the researcher prepared an information sheet with the names and websites of human rights organisations, such as the Equality and Human Rights Commission, for participants who wished to find out more about human rights after the interviews.

5.7.2 Gatekeepers

Care home residents, their relatives and care workers can be difficult to access without directly engaging with a care home. But even in a care home, identifying and approaching potential participants can be difficult for an external visitor. It also poses risks, such as the risk of disrupting the care home environment. In this research, gatekeepers were individuals who provided access to potential research participants. They had in-depth knowledge about the participating care homes, residents and visitors, which enabled them to identify possible interviewees (Holloway and Wheeler, 2002). In this study, gatekeepers were usually the care home managers.

Using gatekeepers raises the following ethical issues (Witham et al., 2015):

- Using gatekeepers reinforces power structures and existing inequalities. This is counter to the ethos of human rights research, which should have at its core the principles of equality, participation and transparency.
- Due to existing power imbalances, gatekeepers may force members of staff, residents or relatives to participate. Potential participants may feel that withholding their consent may have negative consequences.

- Gatekeepers may wish to protect the well-being of care workers, residents and relatives. However, they may also wish to hide or control information by denying access to certain individuals who might have wanted to participate.
- Research participants may feel uncomfortable about speaking frankly if gatekeepers in their care home are aware of their participation. They may fear reprisal or other negative consequences of sharing information and negative perspectives during the research process.

Despite these challenges, working with gatekeepers was necessary and even desirable to minimise disruption to the care home environment and to identify potential participants who had the capacity to give consent. In some cases, the care home managers invited members of staff, residents or relatives to participate. The researcher informed each of these individuals at the outset of their interview that there would be no negative personal consequences if they decided not to participate and that the gatekeepers would not be informed about their choice. The participants were reassured that none of the information they provided during the interview would be shared or discussed with gatekeepers unless they disclosed harm and the gatekeeper would be the most appropriate person to involve.

5.7.3 Informed consent

Ethical social research should include fully informed consent from all research participants (Luff et al., 2011). To give fully informed consent, participants must understand what the research involves and must be able to consent (or refuse) to participate. Informed consent encompasses three elements: voluntariness, information and competency (Cohen-Mansfield et al., 1988). In a care home setting, this means that participants' possible special needs must be considered (Luff et al., 2011). Therefore, the researcher not only provided tailored information sheets and consent forms but also took the time to reiterate the details of the study and ensure that participants had a reasonable understanding before continuing. This included for the researcher being aware of non-verbal cues.

In this study, consent was sought from:

- expert participants (for the expert interviews);
- care home owners and care home managers (for the participating care homes); and
- care home managers, care home residents, care workers and relatives (for the qualitative interviews).

An information sheet and consent form (see appendices) were prepared for each group. Participants were invited to sign consent forms after reading (or listening to) the information on the sheet and

the clauses on the consent form. This provided legal protection for the participant and the researcher (Luff et al., 2011). However, some participants might have felt under pressure to participate in the study (consent under duress). The researcher needed to be aware of this and be sensitive throughout the research process. Therefore, the following measures were also used:

- The participants were not persuaded or put under pressure to give consent.
- The participants were informed and reminded of the voluntary nature of their participation (including their right to withdraw from the study at any time and for any reason, without penalty), and that not participating would have no negative consequences for them.
- No financial incentives were offered to encourage participation.
- The participants were informed that taking part in the study would not provide any therapeutic or service benefits.
- Equality in interaction was pursued as far as possible.

5.7.4 Participation

On the basis of the human rights principle of participation, care was taken to ensure that the participants were included in and given control over the research process as much as possible. The participants were invited to choose a date, time and place for their interview. The techniques used in the interviews were chosen with the participatory ethos underlying this research in mind. The participants were able to direct the conversation by choosing to take pauses, stop altogether, make use of the techniques and so on.

5.7.5 Respect for privacy and confidentiality

Care homes are people's homes. Researchers should be aware of their status as a visitor when entering a care home and respect the participants' dignity and human rights, including their right to privacy (Maschi, 2016). The researcher asked for permission to enter communal areas and private spaces, such as bedrooms. Care was taken not intrude on private conversations or visits from relatives and friends.

In 2009, Hall and colleagues reported on the challenges of ensuring privacy during interviews in care homes. According to their experience, care workers frequently enter residents' bedrooms, even during interviews, and sometimes doors are left open (Hall et al., 2009). Indeed, at times care workers did enter private bedrooms unannounced during the interviews for this study, which were subsequently paused. Doors to rooms were closed before the interview commenced, and if the participants wished to have the windows open for comfort, they were made aware that people outside may be able to hear the conversation.

Another aspect of respecting participants' rights is to treat any information provided by them or attained whilst visiting their care home as confidential. Confidentiality is a key component of ethical research, as it protects the participants from any adverse consequences of their disclosures. It enhances trusting relationships and supports data integrity, as it makes the participants feel more comfortable about sharing information. There were three significant considerations regarding confidentiality for this research:

1. **Disclosure of identity**. Due to the sampling and recruitment strategies used in this study, other people in the same care home may be able to identify the participants (for example, through the use of citations in publications). The anonymity of the research participants, including the expert participants and the participating care homes, was sought and protected throughout the research project. Each participant received an ID number. Transcripts included ID numbers rather than names; thus, they cannot be traced to individuals. Citations in publications add credibility and depth to the research, and the participants were informed of the intention to use pseudo-anonymised citations in the study and publications. The gatekeepers were advised not to share the identities of the research participants with anyone else.
2. **Disturbances during interviews**. To minimise the risk of disrupting the interviews and the risk of breaking the confidentiality and privacy of the conversation, the interviews were held in private spaces.
3. **Data protection**. Respecting the participants' right to privacy and confidentiality includes protecting their data. As little personal data as possible was sought in the participants' consent forms, and no health data was collected. The interviews were stored in line with King's College London's data privacy policy.

5.7.6 Disclosure of harm

The participants could have reported abuse or neglect when discussing human rights and care in their interviews (Bergeron and Gray, 2003). Therefore, it was important to know what steps to take if possible harm was disclosed. The information sheets stated that if a participant disclosed neglect, the researcher had a duty of care to break confidentiality and contact the social care department in the appropriate local authority (GOV, 2019b). Had a participant disclosed that they or someone they knew had been abused or hurt, the researcher would have informed the person that this information needed to be shared.

6 Human rights and care homes: perspectives from the literature

This chapter reviews the literature on human rights and care homes. In later chapters, two short reviews are provided on what is known about the development of the CQC's human rights approach to regulation (Chapter 7) and on the right to privacy in care homes (Chapter 11). A more comprehensive review of the evidence for good practice in respecting care home residents' right to privacy was produced in the remits of this study and was published in a peer-reviewed journal in January 2019 (see Appendix 1).

This chapter sets out the relevant academic contributions that were drawn on to produce a typology of perspectives, which was used to structure the findings of this study, In addition, reviewing the academic literature helped to define the factors (success factors and stumbling blocks) that make the role of human rights in care homes a *potential* rather than an actual one.

Several researchers on social care policy and care homes have used typologies to describe, compare and discuss perspectives on specific topics related to care homes (Wearness, 1984, 1987; Davies, 2003; Trigg, 2018). Trigg (2018) developed a "typology of provider quality orientations" which captured three ways in which care home providers might approach the topic of service quality. These three orientations were "organisation-focused", "consumer-directed" and "relationship centred" (Trigg, 2018 p. 51). Each type has defining characteristics, which including different perceptions of care home residents (as "passive patient", "empowered consumer" or "individual with personhood") and of care (as "process", "service" or "relationship") (Trigg, 2018 p. 50).

Davies (2003) captured experiences of life in a care home from the perspectives of residents, family members and staff, and organised them in a typology of "communities of care". This research described three types of approaches to understanding care homes as communities ("controlled community", "cosmetic community" and "complete community") and their fundamental differences. Such typologies can expose opposing views on the same issue, which may otherwise prohibit straightforward and meaningful discussions on conceptually diffused topics (Kluge, 2000). Trigg's work is useful for understanding the different aspects that allow a typology to take shape. These include definitions of the overall approach to one topic, differing conceptualisations of key stakeholders, and definitions of concepts.

Indeed, it has been suggested that human rights is a topic that attracts several perspectives and approaches. Klug, for example, highlighted that individuals can approach human rights in terms of "philosophy", "scepticism", "politics" or "law" (Klug, 2015 pp. 105–117). As mentioned in Chapter 2, a typology of attitudes to human rights in English society has been identified (Equality and Human

Rights Commission, 2018). The Equality and Human Rights Commission developed this typology to understand its audience better and recommend ways of communicating about human rights to increase support for the concept across the population (Equality and Human Rights Commission, 2018 p. 1). The role of human rights in the English healthcare system is clear: the NHS is a public authority, so it is bound by the HRA. In care homes providing social care for older people, however, the potential role is not as straightforward because of the largely independent care home market and the ambiguous regulatory framework (see Chapter 4). A similar typology of perspectives in this context may support the development of the regulatory framework and inform the future debate on the human rights of older people in care homes.

Four different approaches to the topic ("types") emerged from the literature reviewed in this chapter:

1. **The social, political and adult social care type.** These contributors approach the topic from a policy and political angle, with a focus on the place of care homes in society.
2. **The law-oriented type.** These contributors approach topic from a legal angle.
3. **The normative context shaping type.** These contributors approach the topic from a care home contextual angle, defining how residents should be treated.
4. **The whole-system type.** These contributors take a holistic approach, integrating most of the types above.

Under these types, six sub-perspectives were identified: anti-institutional advocacy; violation-based reactive; care practice shaping normative; equal rights; issue-based; and whole-system. The perspectives from the literature are summarised in Table 6.1.

Table 6.1 *Typology of perspectives: literature*

Type	Sub-type	Conceptualisation of human rights	Conceptualisation of main duty-bearer	Conceptualisation of care home resident	Success factors/stumbling blocks
Social, political and adult social care	Anti-institutional advocacy	Legalistic/analytical	Government	Victim of ageist social structures	Good operational measures to analyse human rights violations, existence of international and national institutions and policies that reflect rights.
Law-oriented	Violation-based reactive	Legalistic	Care homes with grade 1 responsibility (Chapter 4)	Victim of human rights violations perpetrated in care homes	Availability and access to advocacy and legal aid services
Normative context shaping perspective	Care practice-shaping normative	Normative	Care home staff	Rightsholder in the care home	Care home cultures and "ingrained care practice"; Issues of awareness around human rights
Normative context shaping perspective	Equal rights	Normative/analytical	Government/Care home staff	Rightsholder/citizen but living in "different context" from others	Policies and processes in place; Understanding of what it means in practice to have "equal rights"
Normative context shaping perspective	Issue-based	Normative/	Care home staff	Victim of human rights abuse	Specification of implications
Whole system	Whole system	Legal/normative/analytical	Government, society, care home community	Rightsholder amongst other rightsholders	Recognition and awareness of multi-level human rights responsibilities

The overall findings of this thesis reaffirm these types and sub-types. They also add further sub-types, practice-oriented insights and discussion points. Chapter 10 proposes a more comprehensive typology of perspectives, which integrates the perspectives from the academic literature with those that emerged from the study's findings. The findings of this thesis also highlight that the topic of human rights can be an emotive one in the context of care homes. The perspectives were influenced by individuals' own perceptions of care homes, their circumstances and experiences, their

relationships with themselves and others, and their position in the care home system. This was also apparent in some of the academic literature reviewed for this chapter, which largely focused on revealing perceived injustices or poor care and offering solutions that are based on human rights.

The next section of this chapter introduces the methodology used for this literature review. Each perspective is then presented, focusing on the sub-types drawn from the contributions included in this thesis. The four types and sub-types are elaborated on in Chapter 10.

6.1 Literature review: method

The typology of perspectives presented in this chapter was developed from a scoping review of the literature on (human) rights and care homes for older people. "Scoping reviews aim to map the key concepts underpinning a research area and the main sources and types of evidence available" (May et al., 2001 p. 194). Arksey and O'Malley (2005) developed a practical framework for scoping reviews. It includes the following steps: (1) identify research questions and domains, which need exploration; (2) search for relevant literature, for example by using databases and reference lists; (3) select relevant studies according to the research questions; (4) chart the data; and (5) collate, summarise and report the results (Arksey and O'Malley, 2001 pp. 8–9).

Scoping reviews have been criticised because the researcher does not usually assess the quality of the primary studies reviewed (Grant and Booth, 2009; Pham et al., 2014). Critics have claimed that without assessing the quality of the literature, the scoping review will fail to identify gaps in the research. This is especially important for human rights researchers who aim to produce high-quality, balanced research (Coomans et al., 2009; Andreassen et al., 2017 – see Chapter 5). Although the quality of the literature was not assessed for this review, the premises and assumptions on which the literature was based were identified (see Section 6.2). This can give some indication of the quality of the literature (Andreassen et al., 2017)

The review began with the following broad research question: What does the English-language academic literature say about the role of (human) rights in the care and life of older people living in care homes? Because human rights research is multi- and inter-disciplinary (Andreassen et al., 2017), the research was not restricted to one academic domain. However, the following inclusion criteria were applied: the year of publication (from 1998 onwards, as this was the year in which the HRA was adopted to December 2018) and the language (English-language only).

To identify relevant literature, electronic databases and peer-reviewed journals were searched for the following keyphrases: (human) rights and (residential) care (homes); (human) rights and older people; human rights and long-term-care. Further contributions were identified through reference

harvesting. The contributions were considered for inclusion if the keywords appeared in the title, the abstract or the keywords section of the contribution. This limited the scope of the review. It is probable that potentially valuable contributions were missed because of the focus on the keywords. However, to minimise the risk of gaps, any books and articles that were identified as relevant outside the formal search task were also included. In total, 23 contributions were included. There were 15 from the UK, 1 from the United States of America, 1 from Germany, 3 from other Northern European countries and 1 from Australia. The rest were wider international contributions. Articles mostly came from the fields of legal studies and sociology. A list of contributions included in this review is provided in Appendix 4.

Most of the contributions included in this review originated in the UK. However, some focused on human rights and care homes in other countries, notably in northern European countries such as Norway, Finland and Sweden. These were included if they provided a conceptual framework or points of discussion that could be transferred to the potential role of human rights in English care homes. As mentioned in Part I of this thesis, this study is contextual. Its findings are considered in the context of what is known about public perceptions of human rights in England and the English care home system. Therefore, perspectives from the literature had to be adaptable to allow for contextual variety. The literature on human rights in healthcare settings, such as hospitals, was considered "grey" literature and was excluded. This included reports by human rights advocacy and lobby groups, which are considered in other sections of this thesis (e.g section 4.3).

Some of the literature included in this review deals with human rights in nursing homes rather than in care homes. However, most of this literature focuses on general questions of human rights in long-term care in an institutional setting, rather than on the nursing or healthcare components of nursing homes.

6.2 Definitions of human rights and the assumptions made in the literature

In the literature there are three commonalities regarding the definitions of and underlying assumptions about human rights, care homes and older people. Firstly, a 'universal declaration model of defining human rights' is widely adopted. Secondly, most contributions address issues of perceived poor care practice in care homes or ageist attitudes towards care home residents. A human rights approach is suggested as either a solution or at least an argumentative factor to drive change. Thirdly, linked to the emphasis on perceived poor care practice and injustices against older people in care homes, the literature paints a bleak picture of care homes as institutions that violate residents' human rights. The status quo for care home residents is mostly described as gradually losing one's self-identity and being "vulnerable", socially isolated, stripped of citizenship, forced into

communal living, and in need of support to assert one's rights. The commonalities and differences are presented in the following sections.

6.2.1 Defining human rights

Most frequently, the literature defined the concept of human rights as the rights and freedoms contained in the UDHR and the ECHR. Articles authored in the context of the UK often referred to the HRA, using it as a rationalising factor for discussing the topic in the wake of landmark case of *YL v. Birmingham City Council* (see Chapter 4). In some publications, human rights were further defined by grounding values, including freedom, dignity (Kane and Fries, 2017; Oye and Jacobsen, 2018) and the FREDA principles (Kinderman et al., 2018). FREDA was often referred to in contributions that suggest practice interventions to integrate human rights into care practice.

Such consensus on the general definition of human rights was useful for this review. It provided a common ground for offering various perspectives on the potential role of human rights without having to first discuss the meaning of the concept *per se*. Although some rights were considered more salient than others (Cahill, 2017; Bartlett, 2018; Oye and Jacobsen, 2018), the fact that so many adopted the same definition of human rights made it possible to discuss the implications of the entire catalogue of human rights on care home residents. This included their socio-economic rights, such as the right to adequate housing and the right to participate in social and cultural life (Riekkinen, 2015).

However, in some contributions with a legal focus (Cooper, 2002; Dow, 2008), human rights were conceptualised mainly as "human rights law" and, as such, a matter of legal redress for perceived violations of rights under the HRA. In Table 6.1, this is referred to as a "legalistic" conceptualisation of human rights. At times, this conceptualisation was used to identify and analyse the number of human rights violations in care homes and thus determine the extent to which residents are subjected to them (e.g. Townsend, 2006). The conceptualisation of human rights then becomes legalistic and "analytical".

Other contributors considered human rights as either a legal and normative force or a purely "normative" concept (see Table 6.1). Human rights as a normative concept can be understood as a standard-setting concept, which may be grounded in law and regulation but also exists outside it, based on a moral consensus about which rights should be human rights. This understanding of human rights is common in several perspectives, including those on normative practice shaping (Yates-Bolton, 2010; Backhouse et al., 2018) discussed below.

The majority of contributions defined the main bearers of human rights duties as the government and public authorities. However, many authors recognised that care home managers and care workers have a legal or normative responsibility (or both) to protect the human rights of their residents and, in some instances, their staff (e.g. Emmer DA Green et al., 2017).

6.2.2 Assumptions about care homes and residents

Care homes in England suffer from a largely negative image. This "stigmatisation" of care homes as potentially terrible places to live (Johnson et al., 2012 p. 212) pervades much of the reviewed literature. Erving Goffman's (1957) concept of the total institution seems to have had a lasting effect on the authors (e.g. Brownie and Horstmanshof, 2012; Doron et al., 2016 p. 211; Cahill, 2017 p. 99). Goffman defined "total institutions" as physical places, such as a care home, in which "inmates" (residents) life continously, largely cut off from the outside world and society. Activities inside total institutions take place in the presence of others and follow a strict routine and schedule determined by "the authority" to attain the institution's aim. Total institutions strip inmates of their self-identity, humiliate them and degrade them. Care staff are part of the authority, are self-righteous and "feel superior" (Goffman, 1957 p. 2). The statement below is an example referring to totals institutions from one of the reviewed contributions:

> More than half a century has passed since Goffman's depiction of nursing homes and homes for the aged in dark colours of total institutions … In an ageing world, current thinking, planning and resources are scaling up from previous estimates but within this framework for tackling the issue, the people at the centre of it find themselves without voice or choice, echoing the shadows of the total institutions (Doron et al., 2016 p. 211).

Thus, the starting point for many articles in this review is the wish to address perceived injustices, poor care practice or human rights violations in care homes. In general, the human rights lens is considered to be a relatively new one through which to view the topic and propose solutions (e.g. Cahill, 2017 p. 100).

Taking this into consideration, authors implied perceptions of the status quo of care homes as institutions. Older people moving into and living in care homes were often described as victims who were disenfranchised, socially isolated and, as such, vulnerable to discriminatory practices and other abuses of their human rights (e.g. Meenan et al., 2016; Kane and Fries, 2017). This perception is especially the case in the literature on residents with dementia, who may not have the same cognitive capacities as people without cognitive impairments or whose impairment is less advanced.

The authors suggest that these people are especially prone to experiencing human rights violations (Cahill, 2017 p. 125; Backhouse et al., 2018). Care workers (Oye and Jacobsen, 2018) and family members (Lloyd-Sherlock et al., 2018), on the other hand, are often perceived as "villains" and potential perpetrators of abuse. Given their prominence in the academic literature, these conceptualisations of residents and care workers deserve further elaboration here.

It is often acknowledged that care home residents have been – and probably continue to be – subjected to abuse and violence at the hands of care workers, which could amount to violations of their human rights. Furthermore, research suggests that people who are experiencing cognitive and physical decline may feel less capable of making choices, voicing their opinions and demanding their rights than those who are not (Cahill, 2017 p. 125). However, other literature warns that without reflection, using blanket concepts (such as vulnerability or lack of voice) in relation to a particular group may lead to further inequalities and injustices (e.g. Harding, 2017a p. 20). For example, even individuals with severe dementia retain "personhood" and communicate in different ways, perhaps trying to exercise their agency through non-vocalising gestures (Cahill, 2017 p. 126). From this perspective, it is ignorance of such methods of communication amongst care workers, relatives and others, rather than the impairment itself, that can "rob" people of their voice.

Furthermore, common perceptions and the general "victimisation" of residents and "villainisation" of care workers in the academic and other literature reviewed may have contributed to the topic becoming emotive, with many negative connotations. Indeed, a study included in this review (Emmer DA Green et al., 2017) showed that such negative connotations of human rights and the villainisation of care workers by popular human rights discourse in Germany has increased stress amongst care workers in care homes, especially those who are insecure about the practical implications of human rights for their work. It has also been suggested that negative connotations of human rights make it harder to integrate human rights approaches into care practice. This is discussed in Chapter 10, section 10.2.1.

A second common starting point in the literature is a risk-based conceptualisation of care homes. Here, the authors assume that life in a care home automatically strips residents of certain human rights or that particular rights are especially at risk of abuse (Brownie and Horstmanshof, 2012). The rights commonly mentioned as especially at risk are liberty, security, family life and privacy (Cooper, 2002) and the right not to be subjected to torture or cruel, inhumane or degrading treatment or punishment (Backhouse et al., 2018).

Such risks have been attributed to two factors. The first is the institutional nature of care homes, with their process-driven, task-based, custodial or routine-based culture (Oye and Jacobsen, 2018

p. 3). This is frequently argued to be in opposition to individualised, person-centred and personalised services and care, to the detriment of residents' rights and freedoms and in line with Goffman's total institutions. Care home regulation aims to counteract harmful institutionalisation by focusing on quality indicators, such as person-centred and relationship-centred care practice (see Chapter 3). However, many authors in this review considered a human rights approach to defining care quality as a more suitable (and perhaps more powerful) method. Person-centred care is gradually being re-conceptualised as a human rights approach to care by some academic contributors, the CQC and care workers themselves. Thus, it is receiving recognition as a necessary ingredient for any care home that respects human rights.

The second factor is the nature of communal living in care homes. Residents are placed in the company of people whom they did not choose to be with and whose rights need to be balanced (Backhouse et al., 2018 p. 1935). Indeed, some studies, including this one, suggest that to maintain some rights (for example, the right to privacy), the communal living circumstances must be taken into account (Cahill, 2017).

6.3 A typology of perspectives from the literature

This section discusses the sub-types of the perspectives that emerged from the literature (see Table 6.1). Where appropriate, the perspectives are discussed with reference to relevant literature that was not part of this review.

6.3.1 The anti-institutional perspective

From this perspective, human rights are thought of as a framework for analysing human rights issues pertaining to care homes. The framework is also used to question the existence and purpose of care homes for older people in society and adult social care provision *per se*. A human rights lens is applied to arguments pertaining to an anti-institutional movement targeting care homes. Much of the literature in this review shares an anti-institutional sentiment on the basis of which arguments are made. Many of the contributions could be classed under the anti-institutional perspective, promoting (implicitly or explicitly) the idea of human rights as a framework that challenges care homes in society.

An openly anti-institutional perspective in this review is expressed in Peter Townsend's (2006) paper. Townsend considers care homes for older people in England to be a symptom of "structured dependency" created by long-term economic and social policy in England. According to Townsend, older people who are in an environment of structured dependency do not receive the same opportunities and life chances as younger people. Care homes, from his perspective, are custodial

places where people – especially those who have been placed there against their will – are made dependent on others, suffer abuse and experience human rights violations.

Townsend proposed international and national human rights law as a framework for "rigorous analysis" and "anti-ageist" work that could help to identify the injustices that older residents face in care homes (Townsend, 2006 p. 166). He even defined the success factors for making such a role for human rights a reality: "Success depends on good operational measurement – to produce reliable evidence of violations and monitoring progress – and the incorporation nationally and internationally of institutions and policies that reflect those rights" (Townsend, 2006 p. 177). A major stumbling block could lie in the very system of policies this perspective seeks to challenge, if no such rights reflecting institutions or policies are put in place.

6.3.2 The law-oriented reactive perspective

The violation-based reactive perspective is mainly supported by lawyers. They refer to potential legal redress under human rights law for care home residents and care workers (Cooper, 2002; Dow, 2008). From this perspective, the potential role of human rights in care homes is one of legal (re-)action in response to human rights violations in these settings.

One example of this is Jeremy Cooper's (2002) contribution, which highlighted rights that are salient in care homes, such as the right to privacy. He discussed the possibility of legal action when those rights are breached. Dow (2008), on the other hand, analysed the human rights framework governing English care homes and pointed out, as mentioned in Chapter 4 of this thesis, that the HRA is not available as an instrument of legal redress to all residents of care homes.

Of particular value in this literature is the reference to the nature of some rights and freedoms contained in the ECHR as "absolute rights" and others as "qualified rights" (Cooper, 2002). An example of an absolute right is the right to be free from inhumane and degrading treatment, which could take the form of abuse and violence against care home residents. Here, the human rights lens focuses on the view that no form of abuse or violence can ever be tolerated. This can challenge common care practices and habits that are perhaps not widely considered as instances of abuse or violence by care workers, or even by residents and their relatives.

A qualified right is a right or freedom that can be restricted lawfully in some circumstances. Two examples are the right to privacy and the right to liberty. Often, the communal nature of care homes is viewed as inherently against the right to privacy. However, contributions from the violation-based reactive perspective highlight the limits to certain rights that must be considered in the context of a community of people living together. The right to privacy must be protected and respected in care

home settings, but in some instances a breach might not amount to a human rights violation. This holds true for the right to liberty, which can be legally restricted under the MCA 2005, as long as DoLS are in place. Therefore, there are questions about when breaches could and should be legal and what processes need to be followed before any lawful "breach" is made.

Also of value in this literature – and the perspective as a whole – are discussions about the pre-conditions for residents, and indeed care workers, to react to potential human rights violations. Advocacy services and legal aid, which can support residents, their families and care workers to access the legal system, are mentioned as significant for making this avenue available. If such services are not widely accessible, the violation-based reactive role of human rights in care homes can only be a potential one.

6.3.3 The care-practice-shaping-normative perspective

This perspective focuses on the potential of human rights to shape how care and services inside care homes are provided. This perspective is mostly normative and proactive. It approaches the topic from a standard-setting point of view rather than from a reactive, legalistic one. It tends to consider what "human-rights-friendly" care entails and how it can be delivered, rather than focusing on the response to violations of those rights.

There are two angles in the literature on this perspective. The first considers the "point of care": how care workers assume their care role. Contributions from this angle frequently link human rights with existing care standards, such as person-centred, relationship-centred and dignified care (Kelly and Innes, 2013; Cahill, 2017). They tap into the knowledge and evidence around these principles to suggest that, for example, person-centred care equals care that respects human rights. This is not a new idea. The concept of person-centredness as developed by Carl Rogers (1942; 1951) tackles discrimination against people with disabilities by conceiving them not as needy individuals who cannot make decisions for themselves but as people with a self-identity and the capacity for autonomy (Leplege et al., 2007). From this angle the potential role of human rights is limited, because it is either inherent or absorbed by other practice ideals. Thus, the value of a "normative human rights approach to person-centred care or dignified care" may lie only in its potential to promote such practices.

This literature also engages with the potential challenges of providing care that respects human rights. In particular, it considers care home managers' and care workers' legal duty of care (Cahill, 2017 p. 101). Under the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014, managers and workers must keep people in their care safe from harm and minimise risks. However, many care workers perceive this as difficult because they have to balance these "duty of care"

considerations with the duty to protect residents' rights (Cahill, 2017; Backhouse et al., 2018). In some cases, decisions made under this duty of care may even infringe residents' human rights (Backhouse et al., 2018).

The literature argues that in this context, the potential role of human rights is to critically analyse responses to such situations in order to frame more suitable responses (Cahill, 2017). It mentions mechanisms, such as technological aids, for minimising risks whilst protecting human rights as much as possible. This links to the discussion on absolute and qualified rights, and the argument that human rights could help to define the boundaries of acceptable care practice and encourage ways of protecting qualified rights as much as possible.

However, evidence-based research on the impact of human rights training on care workers' practice and residents' quality of life has highlighted difficulties in changing care practice (Kinderman et al., 2018). Although the findings suggested that human rights training could increase care workers' awareness and knowledge of human rights, the training had no measurable impact on their care practice or on residents' quality of life. The authors suggested that care is provided in pre-defined individualised patterns that may be difficult to change without wider organisational and cultural change and strong leadership (Kinderman et al., 2018 p. 70).

The second angle considers the care home as an organisational whole, arguing that a human rights ethos should guide its culture. The emphasis here is on the leadership in the care home and on care practice through care workers (Yates-Bolton, 2010).

6.3.4 The equal rights perspective

The equal rights perspective emphasises care home residents' status as holders of human rights and discusses the implications of this – mostly for the government as the main duty-bearer. Several contributors also refer to the concept of citizenship (e.g. Ferrie, 2010; Kelly and Innes, 2013; Jönson and Harnett, 2015). Focusing on civil and political rights, they argue that care home residents have the right to vote and make their voices heard in political processes. Therefore, this perspective does not concentrate as much on residents' lives and experiences inside the care home. Instead, it focuses on their treatment (or non-treatment) by the government as citizens at large.

The literature from this perspective also discusses the challenges of ensuring that care home residents' equal status as rightsholders under human rights law is respected. Jönson and Harnett (2015 p. 2), for example, developed an equal rights framework for older people in care homes on the basis of the "rights-based" principle of normalisation. They then investigated how to put the framework into practice (Jönson and Harnett, 2015 p. 2). The authors began their argument by

making the broad assumption that older people in residential care often have disabilities and that living conditions inside care homes are different from those elsewhere. They then introduced the "normalisation principle", a concept that is used mainly in Swedish disability policy to enable people with disabilities to live their lives in the same way as people (or citizens) without a disability. Applying this principle to the care home context, Jönson and Harnett proposed a conceptual framework of equal rights for older care home residents. The framework aimed to ensure that residents are not deprived of living conditions similar to those of citizens who do not live in care homes (Jönson and Harnett, 2015 p. 6).

According to Jönson and Harnett (2015), the biggest challenge to implementing the framework is to find external categories of reference for equal living conditions. They ask: "What reference to external category and context could a person who is 80 years old and lives in a residential care setting use to claim rights? ... The lack of standards and norms for older people make it difficult for residents at care facilities to claim rights through the use of a comparison to other similar ages" (Jönson and Harnett, 2015 p. 4). Thus, the actual role of human rights in ensuring that care home residents can live a life that is as "normal" as possible depends on finding suitable categories for benchmarking such normalisation.

Another contributor to the equal rights perspective is Peter Scourfield (2007), an expert in social policy and social work in England. In his article "Helping older people in residential care remain full citizens", he developed the idea of "active citizenship through advocacy" to protect residents' right to full participation in society. He wrote: "Older people in residential care should have the same right to be heard on the full range of issues that affect any community" (Scourfield, 2007 p. 1145). Similar to Jönson and Harnett (2015), Scourfield discussed the challenges of ensuring such equal rights and concluded that high-quality advocacy services must be made widely available to help residents live as citizens.

Lastly, Ferrie (2010) took an "ethics of care" approach to this perspective. She argued that recognising the human rights of those requiring care and providing avenues for addressing "degradation" in care facilities is the "route to ending the dehumanising, undignified and un-autonomous lives lived by many people in receipt of care" (Ferrie, 2010 p.13).

6.3.5 The issue-based perspective

Contributors to the issue-based perspective are interested in particular groups of care home residents or perceived human rights issues. The potential role of human rights is usually to frame, highlight and find ways of tackling the perceived injustices faced by residents. These injustices include a lack of participation in socio-cultural life (Riekkinen, 2015), denial of sexuality (Aylott,

2000), denial of the capacity to consent to sexual activity (Bartlett, 2010), and aggression between residents (Kusmaul et al., 2017).

Riekkinen's (2015) contribution from Finland advanced the topic of care home residents' socio-cultural participation as a human rights issue. Riekkinen (2015) established that under the international human rights framework all people, including older residents of care homes, hold the right to participate in socio-cultural life. She argued that this right is not commonly implemented enough for care home residents, who are isolated from the rest of society. Accordingly, Riekkinen (2015 p. 254) considered it the government's duty to ensure "access, participation and contribution (as far as possible) of the elderly in the local community, that is, in institutions for the elderly, as well as in sociocultural events organized both inside the institutions and outside the institutional walls". She suggested that national policies must be developed to ensure that older residents are included in socio-cultural life.

Bartlett (2010) and Aylott (2000) framed the sexual expression of care home residents with dementia as a matter of human rights. Subsequently, Bartlett concluded that the implications of the Sexual Offences Act 2003, which outlawed sexual conduct involving people with dementia, are "problematic" (Bartlett, 2010 p. 151). Aylott concluded that sexual expression in care homes is covered by Article 8 of the HRA (the right to respect for one's private and family life) and Article 12 of the HRA (the right to marry and found a family). Protecting care home residents' right to sexual expression relies on having "circles of support" and advocacy networks that support individuals to demand that right (Aylott, 2000 p. 435).

The strengths of this perspective are its ability to uncover issues and topics that are relevant to human rights but have not been the focus of regulation, policy or public debate. The inclusivity and equal nature of all human beings, in addition to the interdependence and inter-relatedness of socio-economic and civil-political rights, comes to fruition here. This perspective can open up new ways of considering life in a care home. On the other hand, it is limited by the need to specify the necessary steps, tools and policies to respect, protect and provide for specific rights.

6.3.6 The whole-system perspective

The whole-system perspective combines most of the perspectives mentioned above. The contributors do not necessarily speak of "systems"; however, for the purposes of this thesis, the chosen concept reflects a key characteristic of this perspective. A system can be defined as a collection of interdependent and inter-related components that, through their relationships, function as a whole (Foster-Fishman and Droege, 2010). Systems usually have a shared purpose. In this thesis, the "whole system" includes components that work together to ensure that the human

rights of people in care homes are respected and protected. These components can be organisations, the law, policies, care practice and so on.

The whole-system perspective recognises that people in the care home community are equal rightsholders. It approaches human rights from a legalistic ("reactive") and normative ("proactive") angles, and highlights the multiple responsibilities for protecting human rights at the government level and the care home level.

Emmer and colleagues (2017), for example, argued that in the context of care homes, the potential role of human rights is dual (reactive/proactive), dynamic and multi-levelled. As such, human rights have the potential to shape relationships between people inside the care home, relationships between people in the care home and their local community, and government regulations (Emmer DA Green et al., 2017 p. 2). This takes place through a dynamic process of standard-setting and legal redress when standards fail to meet human rights requirements. Standards are developed further through legal and normative scrutiny. Success factors for such a process include being aware of and recognising the value of human rights in care home settings. A potential stumbling block is a lack of stakeholder engagement (including government officials, care workers and care home residents) in this dynamic process (Emmer DA Green et al., 2017 p. 34).

In another contribution, Carr and Hunter (2010) argued that human rights can enhance dignity through effecting cultural change in organisations. The concept of human rights is not "limited to responding to consequences of abuse, but is about embedding a culture of human rights within organisations" (Carr and Hunter, 2010 p. 325). Therefore, in care homes, the concept can have a reactive and proactive role. Furthermore, the authors proposed that the responsibility for protecting residents' rights lies with multiple stakeholders: public authorities, care homes and courts of law.

6.4 SUMMARY

This scoping review created a typology of six perspectives on the potential role of human rights in the context of care homes. It did so by considering the academic literature on human rights and care homes for older people. These perspectives provided different lenses through which to examine the role of human rights and demonstrated four ways of approaching the topic more generally. In addition, several success factors and stumbling blocks that perhaps define the *potential* rather than *actual* role of human rights in care homes emerged from the literature. These included the wider political, economic and social considerations that guide policy directions on social care for older people. They also included access to legal aid and advocacy services, and challenges regarding care

workers' awareness of human rights. Other stumbling blocks were defined as care home cultures and their ingrained care practices.

PART II: FINDINGS and DISCUSSIONS

7 The Care Quality Commission's human rights approach to regulating care homes and its perspective on the potential role of human rights in care homes for older people

The purpose of element 1 of this study was to explore the CQC's perspective on the potential role of human rights in care homes. During the research and analysis, however, it became clear that from the CQC's point of view there were two roles for human rights in this context. The first was an *active* role, which stemmed from the current place of human rights in the CQC's regulatory function. The second was a *potential* role, which would go beyond regulatory compliance. This potential role was proposed by the expert participants in this research and was reflected in a key CQC document that was analysed for this chapter.

This thesis contends that the CQC's "human rights approach" (CQC, 2014) to regulating and inspecting care services forms part of the human rights framework governing English care homes (see Chapter 4). It has been argued that this aspect of the human rights framework imposes on care homes a grade 2 indirect responsibility to respect and protect human rights, bridging the "responsibility gap" created by Section 73 of the Care Act 2014 (Dow, 2008). This chapter introduces the background and key characteristics of the CQC's human rights approach to regulating. In doing so, it aims to define this aspect of the human rights framework governing English care homes and the active role of human rights in that context.

However, the CQC's purpose is not limited to regulating and inspecting care services. It also shapes knowledge and public awareness of definitions of care quality in England. For example, it publishes general information on care services and provides opinions on the current state and future direction of health and social care services in England. It is this additional purpose that allowed the researcher to explore the CQC's perspective on what human rights *potentially* mean for care homes for older people in England. Thus, the second purpose of this chapter is to provide an interpretation of this perspective.

Section 7.1 summarises the key characteristics of the data sources used to explore the CQC's human rights approach. These sources included CQC experts, CQC documents outlining the organisation's human rights approach, and CQC care home inspection reports (n=104; see Chapter 5).

Sections 7.2 and 7.3 adds to the background information on the CQC (see Chapter 3) by summarising the development of the CQC's human rights approach between 2012 and 2018. It draws on Kenneth Goodpaster's (2007) three-step process of creating value-based corporate cultures to discuss how

human rights are infiltrating the CQC's organisational "mindset" and its regulatory mechanisms. It describes how the CQC defines human rights for the purposes of regulation and the role of human rights in the KLOEs. It also discusses some of the challenges of integrating human rights into the CQC's regulatory work. Using a basic quantitative analysis, this section evaluates the prominence of references to human rights in the CQC care home inspection reports sampled for this research.

Section 7.4 presents the CQC's perspective on the *potential* role of human rights in the context of care homes, as proposed by the CQC experts interviewed and one of the documents analysed for this chapter. The findings presented in this chapter are discussed in Chapter 10 in light of the typology of perspectives and findings presented in Chapters 8 and 9.

7.1 Summary of data sources

To answer the research question for this element of the study, five CQC experts were interviewed, three of whom were care home inspectors. In addition, CQC documents were analysed. These included care home inspection reports published between May 2017 and May 2018 (n=104), which were also collected for the purposes of Chapter 11. Six CQC-authored documents were also considered especially relevant (see Table 7.1).

Table 7.1 Overview of CQC documents analysed for Chapter 7

Title	**Date of publication**
Equality and Human Rights Scheme	March 2010 (CQC, 2010a)
Human rights approach for our regulation of health and social care services	First published in September 2014 (CQC, 2014a), an updated version was published in February 2019. The 2014 version is no longer available (CQC, 2019g)
Human rights approach to regulation infographic	September 2014 (CQC, 2014b)
CQC's Equality Objectives for 2017-19	March 2017 (CQC, 2017a)
The Adult Social Care Key Lines of Enquiry and Prompts: Sources of evidence	November 2017 (CQC, 2017b)
Equally outstanding: Equality and human rights – good practice resource How can a focus on equality and human rights improve the quality of care in times of financial constraint?	First published as beta version in January 2018, updated in December 2018 (i.e. evolving document) (CQC, 2018b)
Inspection reports (n=104) per rating: Outstanding: n=25	Published between April 2018 and April 2017

Good: n=28 Requires improvement: n= 26 Inadequate: n=25	

In addition, references to the CQC's human rights approach on the organisation's public-facing website were included (CQC, 2019h). Other documents referring to human rights, such as the annual State of Care reports (CQC, 2016; CQC, 2017d; CQC, 2018a) and the CQC's strategy documents (e.g. CQC, 2010c; CQC, 2013; CQC, 2017c) were also considered.

7.2 The role of human rights in the CQC's organisational mindset

7.2.1 Developments between 2009 and 2018

The CQC, which began operating in 2009, integrated the regulation of health and social care services (see Section 3.1.2). This laid the foundation for human rights to play an increasing role amongst healthcare providers and amongst adult social care providers (including private care homes). Given that the CQC is a public authority, it must keep to the HRA; therefore, since the early stages in 2009 it has been standard administrative practice to carry out human rights and equality impact assessments of its internal policy papers. Furthermore, by the time the CQC came into existence, the case of *YL v. Birmingham City Council* (see Chapter 4) had moved human rights in care homes onto the political agenda. The Equality and Human Rights Commission (2009) published a report on the role of human rights in improving the quality of health and social care. In line with this, in 2010 the CQC adopted a "human rights and equality scheme 2010–2013", in which it expressed a commitment "to make sure that care is centred on people's needs and protects their rights" (CQC, 2010a p. 11; CQC, 2010c). In 2010, the CQC and the Equality and Human Rights Commission signed a memorandum of understanding (MoU) to define how they would cooperate to fulfil this commitment. This included publishing joint reports on relevant topics and introducing the "cross referral of concerns" (CQC, 2010b p. 4). The MoU has been used 7 times between 2012 and 2018, according to a Freedom of Information Request to the CQC.

However, the CQC's strong early commitment was not reflected in its core business of ensuring service quality until 2014, when it published and adopted a human rights approach to regulating and inspecting care services. The reason for this delay may be that in the early years, CQC's organisational focus was more on operational issues than on service quality (Trigg, 2018 p. 101).

Meanwhile, scandals such as those of Mid Staffordshire NHS Hospital and Winterbourne View Private Hospital stimulated a public debate about the need to improve how health and care services were regulated and inspected (Manthorpe et al., 2016). "Never again events" such as these can

trigger change in care quality regulatory systems (Trigg, 2018 p. 50). The Francis report (Francis, 2013), published in the aftermath of these scandals, recommended a rights-based approach to healthcare services and prompted the development of the new fundamental standards for service quality in the CQC. This paved the way for human rights to have an even more prominent role in defining service quality and regulating care services, including care homes (CQC, 2019g p. 13). It also created a spill-over from healthcare regulation into social care services regulation, as the same standards apply across all care services.

In addition to the effects on quality standards, never again events might have contributed to the protection of human rights developing as a value that is present in the CQC's identity and overall culture. The CQC explained: "Our human rights approach means that our commitment to equality and human rights is embedded in the way we regulate services and how we work as an organisation" (CQC, 2016 p. 1). Therefore, the CQC has a dual commitment to human rights: in its organisational identity and in its regulating function.

To analyse this dual commitment further, it is useful to refer to a theory that explains the purpose of engineering value-based organisational cultures. Goodpaster (2007), in a theory on "conscience and corporate culture", put forward the idea that organisations can have particular mindsets (also referred to as "corporate conscience"), which he defined as "beliefs and basic values with the purpose of guiding management practice". These beliefs and values guide the thoughts and actions of an entire organisation (Goodpaster, 2007 pp. 34–35). Such value-based mindsets can be employed as diagnostic or descriptive tools to help an organisation understand its own structure and evolutionary trajectory. They can also be prescriptive, guiding the actions and behaviour of individual decision-makers, such as chief executive officers (CEOs) and all lower ranked employees. To establish a value-based mindset in an organisation, Goodpaster argued that three processes need to take place: orienting a corporate conscience; institutionalising a corporate conscience; and sustaining that corporate conscience (Goodpaster, 2007 p. 111).

The first step – orientation – involves forming and adopting a moral agenda, which is defined as "an action-oriented set of considerations for guiding business behaviour in an ethical manner" (Goodpaster, 2007 p. 112). This agenda aims to establish a particular corporate conscience. It is mostly the organisational leadership who sets the agenda and is responsible for clarifying its direction. The second step – institutionalisation – takes place through "visible actions", such as leaders making ethical decisions in line with the moral agenda or employees learning how to shape their own decision-making accordingly. In addition, training programmes, symbols, ceremonies and celebrations are established to reinforce the centrality of those ethics (Goodpaster, 2007 p. 161).

Sustaining a corporate conscience relies on "communicating it to the next generation of managers as well as to the wider socioeconomic system" (Goodpaster, 2007 p. 195). Its sustainability also depends on whether individuals in the organisation choose to conform to the ethical values, try to change them or decide to leave the organisation. External responses to the organisation's moral agenda are also important here. External reactions can be negative, positive or neutral, and they can have either reaffirming or destructive consequences for an organisational mindset. If public reactions are neutral (neither affirmative nor resistant), sustaining the corporate conscience is about "whatever energy internally there may be to keep the ethical aspects of the culture alive" (Goodpaster, 2007 p. 195).

Assuming that the CQC is an organisational entity whose "business" is regulating care services, Goodpaster's framework helps us to understand how the organisation integrated human rights into its identity and work explicitly. Although human rights considerations were part of the CQC's identity from its inception, human rights as a value did not infiltrate the organisational culture more extensively until around 2012.

Policy entrepreneurs are individuals who drive policy changes (Trigg, 1018 p. 117) and "take advantage of politically propitious events". Some have argued that these individuals were responsible for the CQC's human rights orientation In particular, David Behan, the CEO of the CQC between 2012 and 2018, was a prominent "human rights-oriented policy entrepreneur" (Trigg, 2018 p. 117). Under Behan's leadership, the CQC publicly adopted the guiding principle of "promoting equality, diversity and human rights" in its strategy for 2013 to 2016 (CQC, 2013 p. 5). Furthermore, the leadership promised to develop a human rights strategy for regulating, monitoring and inspecting services (CQC, 2019g p. 4). These steps indicate that a process of orienting a corporate conscience was taking place, with human rights forming part of the moral agenda driven by individuals like Behan.

Since then, a clear and traceable thread of milestone developments have marked the increasing prominence and institutionalisation of human rights as a value in the CQC. These developments include 'responsibility for ethical decision making on the side of CQC inspectors', 'symbols', 'training programmes' and 'ceremonies'. One of these milestones was the construction of an internal human rights network with "human rights and equality champions". The network spearheads developments in the organisation to make the role of human rights more explicit in all matters concerning the CQC. It includes the Senior Equality and Human Rights Officer and the Equality, Diversity and Human Rights Manager, who joined the strategy and intelligence directorate in 2012. The human rights network also include human rights champions from across the CQC. Membership to the network is

voluntary. The network provides a platform for discussing issues and best practice when applying human rights, for example, in care home inspections. The network has an annual one-day conference, at which members discuss human rights and equality in the CQC. Furthermore, around 14 human rights leaders across England have set up regional human rights networks for inspectors.

The CQC has published several documents that describe the role of human rights in its regulating function. The organisation has also included human rights principles in its inspection mechanisms and arranged training on rights-based care service inspections for around 1000 CQC inspectors between 2014 and 2016, delivered by the British Institute of Human Rights (CQC, 2015b). In 2015, David Behan announced publicly: "All of our inspections take into account human rights and equality and we must continue to embed a human rights and equalities approach across all our work" (CQC, 2015b).

The next section details the milestone public documents that set out the CQC's human-rights-oriented moral agenda. The chapter then turns to how the CQC defines human rights and how it has allocated responsibilities to itself and the care services it regulates for respecting, protecting and implementing human rights.

7.2.2 Major publicly available milestone documents on human rights

For the purposes of this thesis, "major" milestone documents on human rights in the CQC's history (published between January 2012 and December 2018) are those that set out the organisation's human rights agenda, explain how human rights should influence decision-making processes, and provide material to piece together the CQC's perspective on the potential role of human rights in the context of care homes. Two major milestone documents were identified, which are now introduced briefly.

7.2.2.a 2014/2019: Human rights approach for our regulation of health and social care services

The publication *Human rights approach for our regulation of health and social care services* (CQC, 2014a) introduced the organisation's human rights approach to regulation services. The document was updated and re-published in 2019 (CQC, 2019g), but the information it contains – and, importantly, the explanation of the approach – was not changed. Therefore, it is referred to in this thesis as "the 2014 milestone document".

The document aimed to "explain why the CQC needs a human rights approach, its strategy for delivering on their commitment to promote equality, diversity and human rights in their regulation work and give some detail what the strategy will mean in practice" (CQC, 2014a p.4). It did not set out any requirements or standards for providers beyond those in the provider handbooks (CQC,

2014 p. 4). In 2014, there was a strong focus on how human rights aligned with the CQC's identity as the authoritative regulator of care services. For example, the document said:

> We know that many team members – CQC inspectors, Experts by Experience [people with experience of using services] and external professional experts – are strongly motivated by the power of regulation to promote dignity, respect, equality, fairness and choice and control for people who use services. Many team members have years of practical experience to apply to assessing for equality and human rights ... We will tap into this motivation and use these skills to build up confidence in human rights in our inspections (CQC, 2014 p. 22)

However, since 2014 the CQC has adopted a more collaborative way of working, involving external organisations, service providers and service users to develop the approach (CQC, 2019g).

7.2.2.b 2017: Equally outstanding – equality and human rights

The publication *Equally outstanding – equality and human rights – good practice resource: how can a focus on equality and human rights improve the quality of care in times of financial constraint?* marks another milestone in the CQC's public engagement with human rights. It is referred to here as "the 2017 milestone document". It was launched in 2017 and, being a 'work in progress', was updated in 2018. The document is an inclusive effort: it involves people from care services, eight external partner organisations and the CQC's human rights and equality team. Its purpose is to "help providers put equality and human rights at the heart of their improvement work so that the quality of care gets better for everyone" (CQC, 2018b p. 3).

Unlike the 2014 milestone document, the 2017 milestone document does not focus on the CQC's own processes or the role of human rights in the CQC's regulatory mechanisms. Rather, it provides a rationale for care service providers to adopt a human rights approach in their services that goes beyond regulatory compliance. It presents success factors related to human rights in some of the "best" providers: usually, services that have received an "outstanding" rating. The revised version, published in December 2018, offers a link to an online training tool for care service providers, which mirrors the content of the 2017 milestone document (CQC, 2019i).

7.2.3 Sustaining human rights in the CQC's organisational mindset: obstacles and challenges

The sustainability of a value-based mindset depends on external reactions and whether employees adopt the values, try to change them or leave the company (Goodpaster, 2007). The CQC's internal human rights network and the activities introduced above indicate that many employees are interested in engaging with human rights. However, the data analysed in this thesis (documents and

interviews) revealed several obstacles that may threaten a sustained or more central role for human rights in the CQC – and, therefore, in care homes, which must undergo CQC inspections. These obstacles are now briefly discussed.

7.2.2.c Lack of training due to financial constraints and changes in leadership

The CQC's budget has recently been reduced by 13%: from £246 million in 2015–2016 to £217 million in 2019–2020 (National Audit Office, 2017). Meanwhile, the training provided by the British Institute of Human Rights has been discontinued due to lack of funds. New inspectors must now rely on existing documents, *ad hoc* training days and the internal network to build their knowledge of human rights. This may present a challenge, given the National Audit Office's concerns that inspections are not always consistent and objective (see Chapter 3, section 3.1.2). The National Audit Office mentioned that training inspectors is important for reducing variations in inspection standards and building more trust in inspections (National Audit Office, 2017 p. 24).

Public responses to the CQC's human rights approach

According to some of the expert interviewees, a human rights approach was not sufficiently promoted by leadership in local authorities, some relevant civil society organisations and many care services. There has been a focus on related concepts, such as person-centred care and dignity, but not on the rights contained in the HRA. The expert interviewees assumed that the reason for this was the generally negative public perception of human rights:

> There have been these discourse problems in the public whereby human rights are seen as something unfair and unequal. It has been a particular challenge to break through this negative perception and get people to understand that it is about the concepts of human rights as such. (CQC, expert 2)

This mirrors a statement in the 2017 milestone document, which elaborates on public perception:

> Often people see equality and human rights as a problem – not a solution. Especially in times of financial constraint (CQC, 2018b p. 4).

7.3 Human rights in the CQC's regulatory mechanism for inspecting care homes

In the two milestone documents mentioned above, the CQC highlights its responsibilities under the HRA to respect, protect and implement human rights (CQC, 2014a p. 9; CQC, 2019g p. 14). It "embeds" human rights into the way it operates as an organisation (see the section above) and the way it regulates registered services. In the 2014 milestone document, the CQC calls this "its human rights approach to regulating" (CQC, 2014a p. 6; CQC, 2019g p. 10). This section concentrates on

how the CQC has translated its human rights responsibilities into its regulatory function, specifically the documents underlying its inspection mechanism. First, it explains how the CQC defines human rights for inspection purposes. It then introduces the human rights contained in the KLOEs. Finally, it uses a basic quantitative analysis of care home inspection reports to discuss the ambiguity around the CQC's powers to enforce human rights.

7.3.1 Defining human rights for the purpose of care home inspections

The CQC acknowledges that human rights are universal and are enshrined in international treaties and the HRA (CQC, 2014a pp. 9–16; CQC, 2019g pp. 14–19). However, in its regulatory mechanisms, the CQC does not define human rights according to the content of international and national legal instruments (CQC, 2014a p. 9). Rather, it uses the FREDA principles. The 2014 milestone document explained this as follows:

> There are a number of different ways to define human rights in the context of health and social care policy… To develop a human rights approach for our five key questions, we are using commonly agreed "human rights principles". These are sometimes called the FREDA principles – this stands for Fairness, Respect, Equality, Dignity, and Autonomy (choice and control). These principles are considered to underpin all international human rights treaties. (CQC, 2014 p. 8)

According to the CQC, the FREDA principles cover virtually all of the topics and issues that relate to the rights and freedoms contained in the HRA. The principle of autonomy, for example, covers all matters concerning Article 8 (the right to privacy) and Article 5 (the right to liberty). The principle of dignity covers Article 8 again and Article 3 (the right to be free from inhumane and degrading treatment) (CQC, 2014a p. 30; CQC, 2019g p. 34).

The only right not covered by the FREDA principles, the CQC argues, is Article 2, the right to life (CQC, 2014a p. 30; CQC, 2019g p. 12). Furthermore, the CQC does not believe that the FREDA principles apply to "staff rights". Instead, the CQC has adopted a separate definition of staff rights, which is grounded on the principles of employee empowerment contained in the constitution of the NHS (CQC, 2014a p. 30; CQC, 2019g p. 13).

Thus, the CQC's definition of human rights for regulatory purposes encompasses the FREDA principles, the right to life and the rights of staff. It is this definition that currently guides how the CQC integrates human rights into its regulatory function.

7.3.2 Rationale for the FREDA-based definition of human rights

The CQC, in the milestone documents and the interviews for this study, explained that the rationale for adopting a FREDA-based definition of human rights is that it facilitates the integration of human rights into inspection mechanisms. For example, one interview participant argued that the CQC assumed that inspectors and service providers were aware of the FREDA principles but not the articles of the HRA. This lack of awareness, according to the CQC expert, could be an obstacle to integrating human rights into inspection mechanisms successfully. The participant explained:

> We decided to use them [the FREDA principles] because they are known… the concept of equality [for example] people get on the whole and in terms of dignity and autonomy and so on. People grasp those... They do work with those concepts. They might not be used to framing them in human rights terms. (CQC, expert 1)

Furthermore, due to its essential "policing" function, the CQC felt the need to pre-formulate "human rights issues" so that inspectors could categorically look out for them during inspections. These pre-formulated issues are contained in the KLOEs. In the eyes of the CQC, the FREDA principles are easily definable for this purpose, but individual rights and freedoms are not. The following reflection in the 2014 milestone document highlights this:

> Article 8 – the right to respect for private and family life, home and correspondence… is not a very easily understood article. It is broadly defined in law. Therefore, it is difficult for inspectors, providers and people who use services to easily grasp the scope and issues contained in Article 8. (CQC, 2014a p. 9)

This reflection illustrates an example of the thought processes in the CQC around the perceived difficulties of understanding the practical meaning of individual rights (here, the right to privacy) in care homes and other care services. In the CQC's view, the FREDA principles can be integrated into existing good practice approaches because their meaning is easier to understand. The following statement from the 2017 milestone document described this thinking:

> Person-centred care is a human rights approach to care. This is because it is based on respect and autonomy. (CQC, 2018b p. 7)

7.3.3 The FREDA principles in inspection mechanisms and reports

To integrate the CQC's human rights approach into its inspection mechanisms, the FREDA principles were given a more prominent role in an amended version of the KLOEs published in 2017. The KLOEs are questions and prompts that guide inspectors on potential sources of evidence (CQC, 2017a) (see

Chapter 3, section 3.1.2). Although there is no explicit mention of human rights in the KLOEs, there is frequent reference to the FREDA principles. Examples of prompts in the KLOEs are provided in Table 7.2.

Table 7.2 Examples of KLOEs that mention one or more FREDA principles

Key question 1–5	Exemplary "prompt" in the KLOEs	Relevant FREDA principle
Key question 1: Is the service safe?	How do systems, processes and practices protect people from abuse, neglect, harassment and breaches of their dignity and respect?	Dignity and respect
Key question 2: Is the service effective?	What processes are in place to ensure there is no discrimination, including in relation to protected characteristics under the Equality Act, when making care and support decisions?	Equality
Key question 3: Is the service caring?	How does the service and staff make sure that people's privacy and dignity needs are understood and always respected, including during physical or intimate care?	Dignity
Key question 4: Is the service well led?	How does the service promote and support fairness, transparency and an open culture for staff?	Fairness
Key question 1: Is the service safe?	Are there thorough, questioning and objective investigations into whistle-blowing or staff concerns, safeguarding, and accidents or incidents?	Staff rights

Integrating the FREDA principles into the KLOEs means that care home inspectors have to consider human rights when inspecting care homes. The quantitative content analysis of care home inspection reports highlighted that most inspectors mention some of the FREDA principles in their reports. This may indicate the significance that inspectors attribute to these principles when reporting inspection outcomes to the public (see Table 7.3). The principle of dignity is referred to in 94% of the reports, the principle of respect is found in 67%, and the principle of choice appears in 63%. However, the principle of fairness is mentioned explicitly in only 1% of the reports, and staff rights, including the right to share concerns, appears in only 2%. The right to life is not mentioned in any of the reports, but this may be because it is not mentioned explicitly in the KLOEs.

Table 7.3 References to the FREDA principles in CQC inspection reports (n=104)

Keyword	Inspection reports mentioning the keyword (%)
"FREDA principles" (i.e. reference to the term "FREDA", rather than individual principles)	0
Dignity (or dignified treatment)	94
Fairness (or being fair)	1
Respect (or respectful treatment, respectfully)	67
Equality (or equal treatment)	31
Choice (excluding reference to "choice of food/meals" only)	63
Control	25
Right to life	0
Rights of staff (including rights to share concerns, other references to specific staff rights)	2

In addition, and perhaps surprisingly, the concept of human rights is mentioned explicitly in 12% of the reports, in spite of the CQC's FREDA definition and the lack of reference to human rights in the KLOEs. The following example from a CQC inspection report illustrates this:

> Care was planned around people's individual preferences and this included their spiritual wishes. People's diverse needs were considered and their human rights respected. (CQC report, 023)

The references to human rights occurred most frequently in the reports that gave an overall rating of "outstanding" (7 examples in 22 reports). For comparison, human rights were referred to in three reports with a rating of "inadequate" (n=26) and one report with a rating of "good" (n=27). It was not referred to in any reports with a rating of "requires improvement" (n=27) (see Table 7.4).

Table 7.4 Overview of references to human rights in CQC inspection reports

Rating of report	Number of references to human rights
Outstanding	n = 7 out of 22
Good	n = 1 out of 27
Requires improvement	n = 0 out of 27
Inadequate	n = 3 out of 27

Regardless of the rating shown on the report, all references to human rights were positive, praising either care workers' understanding of human rights or the availability of training on human rights and equality in the care home.

One CQC expert suggested that the way in which inspectors refer to human rights or the FREDA principles and related practices in their reports may be influenced by a sense of insecurity about their authority to interpret human rights in care homes. This was especially the case for inspection outcomes with a rating of "requires improvement" or "inadequate", which are frequently challenged in court.

The data for this study suggested that the CQC's choice to use the FREDA definition may also be rooted in an ambiguity around the CQC's interpretative and enforcement powers when it comes to human rights under the HRA. The CQC has made seemingly opposing statements about their powers in relation to human rights. The 2014 milestone document, for example, mentioned that the CQC could address violations of human rights in care homes:

> There is human rights "content" in both our key questions and the new fundamental standards. We will be able to address many breaches of human rights through our own powers... (CQC, 2014a p. 10)

In addition, one expert participant explained that she felt her role as inspector entailed protecting people's rights under the HRA:

> I think that would be my role, really, to make sure that people's rights are being upheld, both in terms of domestic legislation, like the Mental Capacity Act, the Human Rights Act. (CQC, expert 4)

On the other hand, even though the CQC (as a public authority) is subject to the HRA and must act in line with Convention rights, it has no formal legal powers to interpret human rights under the HRA. Neither can it take enforcement action when articles of the HRA might have been breached in care homes or other care services. The following statement illustrates this:

> We are not inspecting for compliance with the HRA... If we find breaches of the HRA that we think the Equality and Human Rights Commission [EHRC] have more suitable regulatory powers to address we can use our Memorandum of Understanding with the EHRC. (CQC, 2014a p. 10; CQC, 2019g p. 14)

Thus, the FREDA definition of human rights may circumvent this ambiguity. If the CQC had used a definition that was more directly based on the law, the CQC and its inspectors might have had to interpret and enforce human rights law: a task that lies with the courts and the Equality and Human Rights Commission. This point cannot be discussed in depth here, but it highlights some complexities

of the human rights framework governing English care homes. It also sheds light on some pitfalls of the argument that all care homes have a grade 2 responsibility to respect human rights.

7.3.4 The consequences for care homes

The CQC's human rights approach to regulating extends responsibility for human rights to all care home providers, even those to which Section 73 of the Care Act 2014 does not apply (see Chapter 4). However, the role of human rights in the CQC's regulatory regime – and the consequences for care home providers – is rather nominal. CQC inspectors do not inspect care homes for "compliance" with the HRA. Rather, they consider the FREDA principles in line with the KLOEs. The inspectors may assess whether care home managers and care workers are aware of the principles of fairness, respect, equality, dignity and autonomy, the right to life, staff rights and what it means to respect those rights and principles in practice. However, care home staff do not have to be aware of the HRA or make a direct link between the FREDA principles and human rights. This raises a question about whether the FREDA principles can be as effective as direct legal responsibility under the HRA in holding care home providers to account when it comes to human rights. However, it is beyond the remit of this thesis to explore this topic further.

7.4 Beyond regulatory compliance: the CQC perspective on the potential role of human rights in care homes for older people

The sections above explained that human rights have played an increasing role in the CQC's organisational mindset and its inspection function. This section captures the perspectives of the CQC experts interviewed on the *potential* role of human rights in the context of care homes. The findings are supported by the documents that were collected and analysed for this study, especially the 2017 milestone document.

The CQC experts interviewed and the 2017 milestone document all implied that the organisation took a whole-system perspective on the potential role of human rights in care homes (see Section 6.3.6). They shared three underlying assumptions, which are discussed below.

7.4.1 Assumptions about care homes, human rights, older people and care workers

The first starting point in the interviews with CQC experts was that care homes were part of society, and society shared a responsibility to treat them as such. As discussed in Chapter 6, some academic contributors to the debate on human rights and care homes shared an "anti-institutional" sentiment. This was not the case for the CQC experts interviewed for this study, who adopted a more "neutral" approach to care homes and acknowledged them as part of society. The following statement illustrates this:

> Care homes are a matter of everyone, not just those who work and live in them. They are a part of society with members of our society living and working in them... (CQC, expert 2)

The second starting point was a law-based definition of human rights. This departed from the FREDA-based definition of human rights that was adopted for the purposes of regulating care homes. Most of the experts referred to human rights as "the rights contained within the HRA", which many considered to be the "foundational law".

The third starting point was that older care home residents were perceived as equal rightsholders, rather than actual or potential victims of human rights abuses. The following statement illustrates this:

> Older people living in care homes have the same human rights as any person who does not live in one. This means they must not be discriminated against, have access to the same services as everyone else, and managers and staff should ensure that they can maintain their lifestyles as much as possible. (CQC, expert 1)

Furthermore, the expert interviewees considered not only the human rights of older residents but also the rights of others in the care home system, including care workers. They suggested that human rights were a matter of relationships between equal rightsholders. However, they did recognise that care home staff had a special role in respecting and protecting residents' rights:

> [Human rights] is key because if someone is living in a care home because of their needs, they need support to fully access their own rights. People rely completely on others to have their rights recognised. It's really important that staff get that and get that it's about someone's whole life, it's not just about those basics that someone is clean and dressed and fed. It is actually about all aspects of their life, have choice, be free of pain and have access to all the other services that everybody else would have. (CQC, expert 4)

7.4.2 The potential role of human rights: at the centre of care homes

The participants proposed a whole-system approach to human rights . The suggested approach would be defined by an explicit holistic engagement with human rights by everyone involved in care homes, from the people who manage, live in, work in or visit them to local authorities, the CQC and wider society. Such engagement might take several forms and be on different levels, but ideally

human rights would be the underlying value of a care home's organisational ethos and amongst external people, such as commissioners and policy makers.

This perspective is also present in the 2017 milestone document. Here, the overall purpose of such a role for human rights – to improve the quality of care – is further defined as follows:

> Any providers could learn from the best providers in using equality and human rights to improve the quality of care. This work involves promoting human rights and ensuring equity in access, experience and outcomes. Importantly, it means empowering people who use services, their families and friends – and staff working in services… (CQC, 2018b p. 4)

According to the expert participants and the 2017 milestone document, such an approach would have five potential effects. These are presented below.

7.4.2.a. Challenging ageist perceptions in care homes (as a step towards tackling them)

Many ageist and discriminatory perceptions exist in society, and they are often perpetuated by people in care homes. According to the CQC experts, human rights in care homes for older people could create new pathways for recognising such ageist and discriminatory behaviour as the first step towards tackling it.

All the CQC experts interviewed said that they frequently came across ageist perceptions of the sexual needs and sexual orientation of older care home residents:

> People always assume that older people stop feeling sexy and this is not true for all of them. There may, for example, be couples who still want to be intimate… What you quite often see is that any kind of expression of sexuality in older care home residents is branded as challenging behaviour. (CQC, expert 5)

These assumptions, according to the experts, meant that people did not receive the care they wanted. Large parts of a person's identity may be lost as a result:

> LGBT people don't receive a service that they want necessarily to receive, for a variety of reasons, and we need to... providers, inspectors, everybody, the general community, needs to get better, don't we, about speaking about those issues. (CQC, expert 1)

Other discriminatory perceptions may relate to ethnic origin or physical and mental disability.

7.4.2.b Highlighting the importance of personalised, person-centred care

From the CQC's perspective, person-centred care and personal outcomes are directly linked to human rights. Person-centred care is a model under which the individual's previous lifestyle, wishes and needs guide the care they receive (see Chapter 3, section 3.2.1). Involving the resident is at the core of this model, in line with human rights:

> [In the person-centred] model the person needing services is not passive… The more that person's influence can be strengthened, the greater the likelihood of equality and human rights. (CQC, 2018b p. 8)

The statement below highlights the way in which one expert interviewee understood the relationship between human rights and person-centred care:

> If a care home respects a person individually, and don't just treat them as a bunch of older people with a blanket fit for all solution, they may not think of it in terms of human rights. But if they get the personalised focus right, there is a chance that they are increasing major human rights. (CQC, expert 1)

7.4.2.c Navigating and finding new solutions for service provision, improvement issues, risks and problems in care homes

From the CQC's perspective, integrating human rights into a care home's culture and work would help to identify risks and problems that had been missed previously. On the one hand, it would provide a framework for finding solutions to problems:

> A human rights and equality lens is something broad… For example, there may be issues where person-centred care will not be able to give you a solution but a human rights lens yes. (CQC, expert 2)

On the other hand, it would focus on people's abilities – including those of residents – and involving people in organisational processes:

> Service user involvement was a common feature [of success]. The focus on what individuals can do and can do now means service users [get involved] in service design and delivery. (CQC, 2018b p. 38)

7.4.2.d Promoting staff equality through value-driven recruitment and management

From the CQC experts' perspective, staff rights and equality should be central to providing high-quality care and working environments. This would mean having a diverse workforce, tackling problems such as staff harassment, bullying and discrimination, and protecting whistle-blowers:

> There is a strong link between the quality of care and equality for staff that requires work on basic fairness and building an inclusive culture that recognises and celebrates diversity. (CQC, 2018b p. 4)

Integrating human rights into the care home culture could also increase staff members' satisfaction with the care they provide:

> Working on human rights for people using services is good for staff… They can gain good skills and experience through finding creative solutions to meet the needs of different service users. Equality and human rights work can energise staff because they like to make a difference. (CQC, 2018b p. 13)

Overall, the CQC experts believed that taking a holistic perspective on human rights in care homes could make "business sense". This is because the quality of care improves when staff are happier and stay in their jobs:

> Improved staff morale [can be] a large business benefit for equality and human rights work because it improves staff retention. This may be particularly true in sectors where there may be problems with staff retention such as care staff in social care [i.e. care homes]. (CQC, 2018b p. 13)

7.4.2.e Increasing awareness of one's own limitations and take-up of external support

According to the CQC, having a vision and mission that are based on human rights could encourage people in care homes to take up external support in areas related to these rights. For example, care homes could get support from volunteers or church groups to provide social opportunities for residents. They could also improve care services by inviting external human rights experts to visit and give advice. External support could also be helpful when human rights present a dilemma and the care home cannot find a solution internally.

7.4.3 Challenges in putting the visionary perspective into practice

The CQC experts spoke about the challenges in making their perspective a reality. They described the following main hurdles: a lack of awareness and negative perceptions of human rights in care

homes; financial thought processes; and the need for collaboration between care homes and external stakeholders, such as commissioners, the regulator (CQC) and policy makers.

7.4.3.a Perceived lack of awareness and negative perceptions on human rights

All the expert interviewees reported that amongst staff, residents and relatives there was a general lack of awareness of human rights and what they might mean in the care home. The following statement illustrates this:

> I really haven't come across an older people's service where I would say that people have an understanding of human rights… This doesn't mean that they don't provide good care but they just don't make the connection with human rights. (CQC, expert 3)

In general, the experts reported encountering negative perceptions of human rights. Alongside the lack of awareness, this meant that the experts avoided speaking about human rights explicitly and resorted to mentioning the FREDA principles:

> For me as an inspector, I don't talk about human rights in that language in care homes because I think it alienates people… Staff are really scared when CQC go in and I think bombarding them with stuff around human rights, they just clam up. (CQC, expert 5)

One expert argued that the negative perception of human rights amongst staff stemmed from a wider negative discourse on human rights in the British public:

> There is too much information peddled around human rights as negative, that the Human Rights Act is a bad thing, rather than being a good thing that's protective… I think unless we as a culture we acknowledge and understand that human rights apply to us all, then we have got a long way to go. (CQC, expert 3)

7.4.3.b Negative perceptions of funding needed to put human rights into practice

In the 2017 milestone document, the CQC recognised that financial constraints may force care homes to reduce spending on some items. This may reduce staffing levels and, therefore, the quality of care.

However, according to the experts, financial constraints are not an obstacle to realising human rights in care homes. Rather, the challenge is that care home providers and managers perceive that integrating human rights into their organisational culture may necessitate additional expenditure.

There are some arguments that a human rights approach could help to maintain or even improve service quality in times of financial hardship. However, no economic evidence for this could be found and the CQC does not refer to any such evidence in its documents. Ultimately, it is a matter of care home managers' understanding of mechanisms to integrate human rights and budget choices.

The need for system-wide collaboration

Making this perspective – and its potential outcomes – a reality would need collaboration throughout the system. The same understanding and vision of human rights would need to be supported and embraced by local authority commissioners, their local authorities, policy makers and the CQC:

> Providers cannot do this work alone. They need support from commissioners, regulators and policy makers to put equality and human rights at the heart of quality improvement. Empowering people and communities is essential to advance equality and human rights. To do this, health and social care leaders need to look beyond provider boundaries. (CQC, 2018b p. 34)

In general, the CQC experts felt that a culture change would need to take place in wider society in order to give human rights a more central and practical role in care homes:

> Unless we change the negative culture around human rights, I think we are going to struggle to actually speak about human rights terms in a meaningful way in care homes. (CQC, expert 4)

7.5 SUMMARY

This chapter considered how the CQC developed a human rights approach by building a value-based corporate culture. From this perspective, the sustainability of the CQC's approach is not guaranteed but depends on several factors. Furthermore, as part of the human rights framework governing English care homes, the CQC's approach compels inspectors to take account of human rights – or, rather, the relevant KLOEs with reference to the FREDA principles. On the other hand, this approach does not require care homes to respect the HRA. The chapter also considered the data that suggests a potential role for human rights in the context of care homes. It investigated the perspectives of the experts interviewed for this study and the CQC's human rights milestone documents. A whole-system perspective was presented, with several potential outcomes and challenges for care homes.

8 Perspectives of care home managers and care workers

Chapters 8 and 9 capture the perspectives of care home managers, care staff, care home residents and their relatives on human rights in care homes as explored under element 2 of this study. The findings for each participant group are reported separately. This risks overlap and repetition in the text. However, the rationale was to capture the perspectives of each participant group – and, indeed, each individual – as far as possible in order to avoid over-interpreting the findings or losing contributions. Chapter 10 integrates these findings and discusses them conjointly.

As explained in Chapter 5, slightly different semi-structured interview guides were used for each participant group and four coding frameworks were produced. Therefore, in this thesis the sections on each group differ according to the themes that emerged from the interviews. Nevertheless, there are some commonalities between the sections. For example, each participant group offered definitions of human rights and associations about the topic. Furthermore, each group spoke about how they perceived care homes in society, older people and people in the care home community. These findings set the scene for exploring the perspectives on the potential role of human rights in care homes (see Chapter 10).

Chapter 8 begins with an overview of the key characteristics of the participating care homes and the people in those care homes who took part. It then presents the findings from the qualitative interviews with care home managers and care workers in the four participating care homes. Chapter 9 does the same for residents and relatives. The findings on the right to privacy are presented in Chapter 11.

8.1 Care home research: sample overview

This research took place in four medium-sized care homes for people aged 65 years or older, with and without cognitive impairments. Three of the care homes had a CQC ratings of “good”, and the fourth had a rating of “requires improvement”.

Across the four participating care homes, 43 people were interviewed. The number of people in each participant group is shown in Table 8.1.

Table 8.1 Overview of sample for element 2 – care home research

Participant group	Planned sample size up to:	Actual sample size
Care home managers	n=4	n=4
Care staff	n=20	n=18
Residents	n=12	n=10
Relatives	n=12	n=11

The actual sample size was lower than initially planned, but this was the researcher's decision. Each interview involved a journey to one of the participating care homes, each of which were located around two hours by train from London, and intruded on the care homes' environments and daily routines. Once the sample size shown in Table 8.1 had been met, an initial analysis of the interviews was conducted and the decision was made that enough data had been collected. Table 8.2 presents the key characteristics of interview participants.

Table 8.2 Key characteristics of interview participants

Participant group	Number interviewed	Characteristics
Care home managers	n=4	● All registered care home managers with 10 or more years of experience in the job ● 100% White-British ethnicity ● 3 female, 1 male
Residents	n=10	● 7 female, 3 male ● Aged between 77-97 ● 60% aged 85 plus ● 100% White-British
Staff	n=18	● 2 male, 16 female ● 1 Asian, 3 Eastern European and 15 White- British ethnicity ● Aged between 19 and 50 with average age of 34
Relatives	n=11	● 5 male, 6 female ● 1 Asian-British, 10 White-British ethnicity ● At least 1 LGBTQ+ background ● Aged between 53 and 72 years with average age of 62

In terms of the inclusionary quotas described in Chapter 5, the researcher interviewed four members of staff with either a BAME or an Eastern European background, one relative with a BAME

background and another relative with an LGBTQ+ background. As explained in Chapter 13, the lack of diversity in the sample is considered a limitation.

8.2 Care home managers

This section reports the findings from the interviews with care home managers. Four themes emerged during the coding process, which have been translated into the sections below.

8.2.1 Care homes, older people and their families: perception and associations

The participants were not asked for their opinions about care homes for older people in England in the interviews. Nevertheless, all care home managers wished to express their perceptions or associations in this regard. These related mainly to the relationship between care homes, residents, residents' families and local government. They also related how they viewed older people in general; that is, as a group that lacked agency, was discriminated against in wider society and lacked knowledge about their rights.

One of the care home managers, for example, felt that the existence of care homes for older people was a symptom of a "failed society" and linked it to a lack of family engagement with older relatives:

> Like a wild animal you have been put into an environment that is alien to us. We lock all our elderly away because there is nobody at home to look after them... But our elderly and care homes are especially suffering because of lack of family engagement. (Participant 102)

Another manager believed that care homes for older people were facing operational difficulties but were not being given financial and other support from local authorities, which did not want to acknowledge their responsibilities to older people:

> We are all alone. Have we got the support from local authorities? No. They won't support you. It's the old saying, "They are old. I don't want to waste money on them." (Participant 103)

Two of the managers spoke about older people moving into a care home. The managers associated this with loss of agency, stigma and trauma:

> Older people coming into this type of setting must be a form of bereavement. Everything has been given up. You feel like you have been rejected by your family. It's a stigma that is in most heads. Is your family going to look after you or are they going to put you in a home? (Participant 104)

They highlighted the role of relatives, who decide to "put" someone into a care home, and associated this with feelings of guilt. These managers maintained that guilt directly affected relatives' interaction with residents, resulting in relatives either not coming to visit or finding it difficult to make decisions for family members with a cognitive impairment:

> For a lot of people there is this problem of having to deal with the great trauma and guilt of putting somebody into a home... often the families have to take over to make decisions for residents. It's tricky for them to know whether they are doing the right thing. (Participant 101)

> I think the stress level at home and the guilt because as human beings we feel guilty … And people are riddled now with guilt for leaving their elderly parents and not having time to look after them. (Participant 102)

With regard to human rights, some of the participants assumed that older residents did not know anything about the concept:

> If you think the people that have dealt with the rights, human rights and things now, over the years, they are not this generation. The people who have implemented rights are a whole different generation. (Participant 102)

8.2.2 Human rights: definitions

All the care home managers defined human rights as universal and equal entitlements for all human beings. They felt strongly that older people had the same rights as everyone else:

> We all have rights. Our residents have the same rights... (Participant 101)

> Everyone is entitled to have their voice heard and people less able to fight for their own human rights should have advocates to speak up for them. (Participant 104)

One manager gave a more explicitly legal definition of human rights. This manager referred to the law, whereas the other participants in this group did not directly make that link:

> Everybody has got the same rights… everybody is equal. You shouldn't distinguish between young, old, male, female… It's the law. It's written down in stone about human rights... (Participant 103)

8.2.3 Human rights: associations

The majority of the care home managers associated the concept of human rights with the principles of "equality of people", "voice", or "being heard". The ability – or inability – to make yourself heard and understood as an individual was at the centre of their ideas. In the statement below, the manager associated human rights with equality and defined it as the need for mutual understanding amongst individuals:

> Interviewer: What first comes into your mind when you think of human rights?
> Participant: I think what goes hand in hand about what you expect and what others expect from you. Equality is making sure sort of what your beliefs are and somebody else's as well. (Participant 103)

In the second illustrative statement, the participant explained her passion for supporting groups of people who experienced disadvantages or did not have a voice:

> Human rights for me is… a passion against the unfairness in the world and people that can't speak up, because older people and children can't speak up for themselves, I think it is really important that everyone has their voice heard and feels empowered… (Participant 104)

A third participant also associated human rights with the ability to converse. The participant referred to ineffective communication when one person speaks and another hears but does not really listen. The participant put this association into the context of communication between care staff and residents in a care home:

> People speak and we hear. But do we actually listen to what they are really saying? Sometimes a resident will explain something to you and very often we haven't got the time to dig deeper and to listen how they are really feeling… Something that may be really important to them and we are probably not looking into it as much as we should. (Participant 102)

One manager felt that the government had a duty to do more to support people who lack voice and money:

> It's written down about human rights and yet it's just "leave it". Don't bring it to the forefront. Just nod. Ruffle your feathers and hope it will go away. Unless you have got… voice and money, you can't do anything. (Participant 103)

A fourth manager did not focus on equality and being heard. Rather, this manager associated human rights with fear and losing the freedom to act on one's personal need for touch and affection. For this participant, human rights were not as closely connected with empowerment. Rather, the participant saw human rights as potentially counter-productive to meeting human needs:

> I think quite often [the meaning of] human rights get forgotten. We forget what we are here for and I think that sums up that everybody needs to have touch and affection and not be afraid of that and I think that the way human rights sometimes go can actually prevent that because people are fearful because "oh it's against my human rights" whereas before it was quite free. (Participant 101)

The managers made various links to human rights in care homes. One manager felt that care homes were inherently risky places for human rights. She associated living in a care home with lack of privacy (see Chapter 11) and loss of freedom:

> As human beings, we were not born to be trapped, all of us together, living in a small space [speaking of a care home]. The freedom is taken away from them [the residents] and the privacy. (Participant 102)

Consequently, this manager expressed concerns about using human rights language with care home residents, as she felt it may evoke negative emotions in them:

> You are opening a can of worms [when speaking about human rights], because you start to make them think about the things they have lost… and how they have lost their freedom… They just think, "What's it got to do with us? Why are you asking me about my money? What has it got to do with you?" (Participant 102)

Another manager made a link between human rights and residents "demanding" or not demanding their rights. This manager argued that new technology is making more information about human rights available to prospective residents:

> [Talking about human rights in care homes] has been quite closed. It's something that people don't want to talk about… The older generation [of residents] that sort of are here now, maybe weren't as clued up on human rights… With new technology, the new generation coming through will be so much more knowledgeable and perhaps more demanding. (Participant 103)

Two managers associated human rights with legal mechanisms, such as DoLS and Do Not Resuscitate Orders:

> You could maybe class a DoLS as an imprinter of human rights. (Participant 103)

8.2.4 The potential role of human rights in care homes

The care home managers offered a broad range of views on the role for human rights in care homes. These views depended on how the participant approached the topic, either from a political/adult social care policy point of view or from a care-practice-shaping perspective. At times, human rights were framed as a tool that could be used to achieve a certain outcome; at other times, protecting residents' human rights was the aim in itself.

8.2.4a Human rights as a tool to highlight the damaging effects of resource constraints and radically re-envision adult social care

One manager considered that human rights issues could be singled out in care homes in order to challenge the current adult social care system. This manager felt that human rights are especially relevant for residents who did not choose themselves to move into a home:

> There is a big difference between you being in a care home because you need to be in a care home or you are in a care home because you chose to be here. Human rights goes out of the window when you are here because you need to be here rather than when you chose to be here… (Participant 102)

This manager proposed two solutions to this perceived inherent risk to people's human rights. Firstly, the participant proposed a solution to the resource constraints faced by care homes, which she considered were mainly to blame for violations of residents' human rights. This could be offset with more engagement from staff and families:

> With human rights, we do know what the human rights consist of and we do know what should happen... There are so many times that human rights are not met and could be met. If there were more staff or more volunteers and family members helping us. (Participant 102)

Secondly, this participant suggested a radical change to adult social care provision in England: to make care homes free of charge. This would encourage more older people to choose to live in care homes. If individuals had chosen to live in a care home, they would not feel the same negative effects as someone who had not made that choice:

> Government needs to say, actually, care homes are a good alternative [to staying at home]. But we have to put money into them, so they become better. It has to be free for everybody and then people will want to come in… (Participant 102)

8.2.4b Human rights and care practice

Two care home managers saw that human rights had the potential to shape care practice. One of them felt that human rights already meant that residents must be involved in making decisions about their life in a care home:

> They have a right to decide what to do and what they don't do, within reason… You can't just take it away, because they have got dementia… (Participant 103)

> Just because you are coming into communal living, it doesn't mean that you shouldn't be treated exactly the same as you would in your environment… carers [care workers] can't enforce anything on anyone just because they come into a care home; they have still got their rights. (Participant 101)

To gain a better understanding of the extent to which these two care home managers felt that human rights were already defining care practice, they were invited to share their definition of "good care". Neither of the participants mentioned human rights explicitly in this definition, which may indicate that they did not consider human rights to be a concept for care practice. Nevertheless, their definitions of good care and human rights in care homes were mostly aligned (see Table 8.3).

Table 8.3 *Comparative statements defining good care and human rights in care homes*

Participant	Definition of human rights in a care home context	Definition of good care
103	They have a right to decide what to do and what they don't do, within reason	Good care is to the individual. Listening to them. Encouraging them to participate and making sure their needs are met and cared for
101	Just because you are coming into communal living, it doesn't mean that you shouldn't be treated exactly the same as you would in your environment	Respecting everybody as individuals. Respect, giving people the opportunity to choose the way that they live their life and the way that they have the care. Not forcing it, you're just allowing them to be normal

When speaking about the role of human rights in shaping care practice, some manager also mentioned potential limitations. One participant felt that the right to make decisions must be balanced with individual risk and should therefore be limited to "wise decisions". If a manager or care worker deemed a resident's decision to be risky, the care home staff would try to convince the resident to change their decision:

> They have a right to decide what they want to do and what they don't want to do as long as they make a wise decision and it doesn't place them or us at risk… It's about trying to coach them into what you are thinking and actually bringing them on board to participate in that decision. (Participant 103)

8.2.4c Human rights and organisational ethos

One care home manager felt that human rights were a top priority in managing a care home and that they should guide the care home's ethos. The manager believed that the human rights of staff and residents were intertwined:

> I am very passionate in a care home setting that human rights is top on the agenda for care staff to be aware and obviously to protect the rights of care staff… You can't expect care staff to respect and implement human rights with older people unless they are valued themselves and their rights are protected. (Participant 104)

In terms of staff rights, the manager mentioned three areas of importance. Firstly, the right to speak up, be listened to and get feedback:

> For human rights and staff it is important to make sure that they have a voice… it's about having a voice to speak up in a care home environment and to be listened to and to be fed back on. (Participant 104)

Secondly, the right to be protected from discrimination and to receive information and to reach out to external support groups:

> We have a lot of staff with different backgrounds and sexualities here, with an LGBT background… that their rights are protected as well. Sometimes working with older people, especially living with dementia, there may be some behaviour that care workers are exposed to and if you just say "well, that's just how it is" without listening and putting something in place with that carer [care worker]… There are lots of support groups outside the home and it is about helping them inside and putting them in touch with these groups too. (Participant 104)

Thirdly, the right to fair working conditions and wages:

> It's about valuing the staff. When their rights get protected and they are valued, this trickles down to the older people they are looking after. (Participant 104)

This manager felt that residents' rights could shape care practice and highlight other areas where individuals could be supported in a care home environment. The manager believed that human rights were about seeing individuals for what they can do and finding ways to help them do it, rather than focusing on what they cannot do.

8.3 Care workers

This section presents the findings from the interviews with care workers. Although some of these themes reported below are the same as the ones reported in the section on care home managers, most of them are different.

8.3.1 Perceptions of older people and perceptions of themselves as care workers

Some of the care workers shared their perceptions of older people, particularly older care home residents. Most of these participants felt that residents were vulnerable, powerless or excluded from society and needed protection. Many of them expressed the view that their role as care workers was to protect residents:

> You've got to remember they're people, they're not back in their day, it's we're looking after them, so bless their hearts, they are vulnerable people, they need their

> own right to speak out, because we do; we can tell them "yes" and "no", we can tell people "I believe in this, or this culture", and other people, so why can't they? (Participant 310)

> I think… when we get older, I think we're sort of labelled, they get labelled... Talking about it now is quite upsetting... us as carers [care workers], we would like to have more time with them, and I know a lot of places, they don't have the resource to do that. It's easier just to sit them down. They're left to their own devices, sort of thing. We do try and move around, when everyone comes downstairs and we try and do different activities with them, but not when it comes to anything really serious or important. (Participant 314)

> Sometimes it can be hard if they don't appreciate what you are doing. It's just as frustrating for them, isn't it? They don't wish to be here, some of them. But, they have to be. You just have to be lenient with each other. (Participant 306)

One person spoke about residents with dementia. This participant felt that staff and other residents misunderstood individuals with dementia. She also felt that people with dementia were "more grateful" to staff caring for them than other residents are:

> I find the dementias [people with dementia], I find they're more grateful than some that have got their faculties. Some of them can be quite nasty towards the dementias maybe… And misunderstanding… When we do our training it's quite interesting to talk about dementias, there's so many of them… Dementias can't express their feelings and that, some get a little bit upset and things like that. I find sometimes... I suppose it's the young carers [care workers], haven't got a lot of patience, sometimes, with them. (Participant 304)

Two participants felt that older people were "old-fashioned" or "racist". They felt that although this was a challenge for care staff, it was their duty to respect residents' views or not take any notice:

> When they are elderly, they are mostly racist. They have been raised that way… I think you just, you have to take their views and respect they are old-fashioned and they were brought up differently to us as well. They have different views. (Participant 306)

8.3.2 Awareness of human rights in participants

This study did not use an indicator or mechanism to measure the participants' knowledge about the topic of human rights. The participants were told that the interviews did not intend to test their knowledge. Nevertheless, four participants felt unable to comment on human rights and another three felt that their level of awareness or knowledge was low.

> Interviewer: When you first hear the words human rights, what comes to your head?
> Participant: I haven't got a clue, actually… Just about what rights I'm entitled to, I suppose, I don't know, and what rights the residents are entitled to, basically everyone, actually. That's basically it, really… Would human rights be applicable to me? (Participant 309)

> Interviewer: When you hear the word "human rights", how does it make you feel?
> Participant: I haven't really thought about it, if I am honest. (Participant 312)

Some of these participants said that their lack of awareness and knowledge evoked negative emotions in them at times, and some said that they would like to be more educated in and knowledgeable about human rights. Indeed, some felt that everyone working in care homes should be educated about the subject:

> Participant: I don't really like know a lot. I don't think like, am I a really bad person, because I don't know anything like, hadn't really thought about it…
> Interviewer: Do you feel like you should know about it?
> Participant: I think I should know like a little bit more about it and maybe think about it a bit more and things like that.
> Interviewer: Why do you think that?
> Participant: Probably because it's important to know what it means and…
> Interviewer: Is that something you would like to as well?
> Participant: Yeah. I should probably know a bit more information about it. (Participant 312)

> Participant: To me it's like a cloudy topic [human rights], sort of thing. Sorry.
> Interviewer: How do feel, because you say you should be talking about it, why do you feel that way?
> Participant: Because I think everyone, we should all have, we've all got rights, haven't we, we should all be able to talk amongst ourselves. (Participant 314)

> Participant: I would like to know a bit more about human rights… I know my side of what I think, but I'd actually like to know what the whole final lot is about. (Participant 310)

8.3.3 Human rights: definitions

Most participants – even those who felt that they had a low awareness of human rights – provided a definition of the concept. In most cases, this definition included a reference to the universality and equality of human rights. The participants tended to define rights as entitlements belonging to every human being, regardless of their age or physical impairments:

> Everyone should have human rights. That is their entitlement, everyone has rights in every shape and form don't they, really. You have got people in dementia. They have their human rights. (Participant 307)

One participant defined human rights as a certain standard that society should reach. Another participant defined these rights as "fundamentals of daily living" and mentioned several rights that are enshrined in the UDHR:

> Freedom. The right to express your opinion without fear of contempt of violence. Basic human rights. Food. Water. A roof over your head. An income of some sort. Those fundamentals of daily living… (Participant 317)

8.3.4 Human rights: associations

Most participants associated the concept of human rights with principles, such as fairness and voice, individuality, and care and compassion. These associations reflected how the participants felt about human rights in general and what was particularly important for them:

Individuality:

> I would say human rights is about people's individuality. Everybody is unique. Everybody's views will be different. (Participant 317)

Fairness and voice:

> I think it's a voice for people. (Participant 315)

> We should all have, we've all got rights, haven't we, we should all be able to talk amongst ourselves. (Participant 314)

Care and compassion:

> Caring, compassion, basically following the human rights that's what it means. (Participant 302)

Many of the participants who associated human rights with the principles above also linked them to law and legal mechanisms, such as DoLS, safeguarding or data protection:

> …human rights is the foundation of all. Equality and diversity. Data protection. Mental capacity. Safeguarding. It underpins everything. (Participant 317)

Some participants associated human rights with violations, such as being deprived of freedom:

> I tend to think of people who are imprisoned just because they have a different faith to the place where they live. (Participant 313)

Two of them felt it was a topic that is relevant "globally" or applied to people in war situations.

> I'm thinking globally… My understanding of human rights is people who are victimised for their beliefs or anything like that that comes to mind. People become imprisoned, killed. (Participant 318)

> To me when I hear human rights, I would immediately think about people in war situations… (Participant 308)

However, the participant who associated human rights with war also (later in the interview) associated it with people being "difficult" and awkwardness:

> I don't like the phrase "human rights". The phrase annoys me. To me, it brings up somebody who is going to be difficult about a situation, who is awkward. (Participant 308)

8.3.5 Human rights and participants' care homes

Most of the participants thought that human rights were relevant in care homes for older people. This was mainly because they believed that residents had human rights.

> If I reflect it to my work, really it's the same thing; they should have basic human rights of freedom, choice, respect, food, safety, warmth, all those type of things and being treated as an individual, that's what I would think within a home. (Participant 308)

> Human rights are relevant in care homes because the people we – they all have the same human rights. Just because they are here it doesn't mean they lose their rights. (Participant 301)

However, frequent links were made between care homes as inherently risky places for human rights, lack of choice and powerlessness amongst residents:

> I feel, at times that, people who live in care homes, sometimes their human rights are taken away from them. (Participant 313)

> Human rights are sort of relevant in care homes because you are dealing with people without capacity so we are taking away their voice. (Participant 314)

> Human rights matter at work for residents because they might feel like they're powerless because we are looking after them; we are there for them and they might feel like they can't change what they want to do any more... They might feel like they can't choose anything because we're their carers [care workers], so we choose for them, which also makes them frustrated. (Participant 303)

Furthermore, many of the care workers associated human rights with "poor" care practice and bad care homes. A common theme was that participants referred to their own workplaces as rights-respecting care homes. Often, participants told stories about "other" care homes that, in their opinion, were not good ones:

> Interviewer: How do you think human rights are relevant for care homes?
> Participant: They are respected, especially in this house… In this house I guess it is respected. (Participant 302)

> Interviewer: Has there been a time at your workplace where you have had to like expressly think about human rights?
> Participant: Yeah, well, in my previous job, I had to where I worked before report someone to the CQC. They had not been nice to a resident. They didn't have their human rights then, really. (Participant 301)

> [In this care home, the residents are] included, definitely respected, and they feel safe and valued… (Participant 316)

> It's good [referring to the care home]. I enjoy it here. The other care home [in which the participant worked previously] was a different story. (Participant 309)

8.3.6 The potential role of human rights in care homes

This participant group offered several perspectives on the potential role of human rights. Most of them saw this role as one that could shape the way they provide care. However, some members of staff offered alternative perspectives. The perspectives are described below.

8.3.6a Law-oriented: reactive perspective

One participant felt strongly that human rights as a legal and regulatory framework could play a role only in care homes that fall below a certain standard. Specifically, the participant felt that human rights were relevant to poor care homes:

> When a care home really is in a state, that's when human rights that's when you have to have these things... I have had a few care homes that have everybody on soft diets because it is easier and have everybody on pads because it is easier. We can't have that. So that's when these rules have to come into place. (Participant 315)

8.3.6b Equal rights perspective

One participant took an equal rights perspective, which considered that care home residents were equal holders of human rights. From this starting point, the participant felt that the government was infringing on residents' human rights by not giving care homes the means to engage their residents in activities outside the home. Therefore, this participant highlighted that protecting and respecting residents' human rights is a matter for the government as well as the care home. She suggested some ideas for how to protect residents' rights:

> These people need to be taken out every so often, perhaps for a cup of tea in the local nurseries. I think they [the government] are infringing on their human rights to freely go out… There is just not enough money being ploughed into care homes so that people can live freely and like getting things like a minibus to them out. (Participant 313)

Some participants made a link between human rights and the working conditions for care home staff. However, none of them went into any detail about what this means in practice. The most common perspective was that staff had equal human rights, which should be respected. One participant claimed to have been the victim of racist abuse, which, according to her, was a matter of

equality. To this participant, the concept of human rights is a tool for identifying, framing and speaking about a topic that is a problem in her work environment:

> Some consider myself a foreigner. We once had a resident in here who doesn't like us [referring to care workers with a BAME background]… But we are all the same in here. Sometimes they treat us as a slave. In my position I have the same rights as your rights. (Participant 305)

8.3.6c The role of human rights in shaping care practice

Most of the care workers saw that human rights could play a role in shaping care practice. In their interviews, they defined what human rights meant to them in a care home and how that translated into care practice. This included giving residents choices, listening to them and spending time with them. The following statements illustrate this:

Choice and decision-making:

> Even if they don't have the capacity… they still have the right to make these decisions. (Participant 301)

> It's their rights, even though they are not able to say "yes" or "no", "I want this" or "I don't want this". You have to sort of kind of implement it in your own way, sort of thing. (Participant 307)

> Every single resident you have has a right to do what they want, eat what they want and choose what they want to wear, and we're just there to support them. (Participant 316)

Speaking, having a voice:

> I know of human rights, just giving them their voice… giving them the right to speak out. (Participant 310)

> Everyone has the right to be listened to, to live their life and be supported to live their life how they choose to, so I think it's very important in a care home setting that we listen to the people who are living here, as well as the people who work here… (Participant 318)

Being listening to and being included:

> It's just having time for them, really, and well, they can give their time, it's just listening… They've got their own feelings, and they want to express themselves just as much, regardless of what we might think. (Participant 314)

Two participants linked human rights in care homes directly to person-centred care. One of them felt that not following a person-centred approach resulted in abuse:

Person-centred care:

> I think all we do here at this care home and across the whole organisation is actually about being person-centred, which is another phrase for human rights. (Participant 317)

> Interviewer: When you first hear the words human rights, when you heard it earlier when we came and spoke to you, what came into your mind?
> Participant: Well, person-centred care. Where you've got to give them the choice. Say you're doing a tea round and you'd offer them tea, coffee, Horlicks, juice, water, that's within their human rights, instead of just assuming a cup of tea. You have to ask them, like, "Is it okay to lift your legs?" because we're all human. I wouldn't want someone to lift my leg up and I've not asked for that, or if they want to wash, if they don't want to wash, and you've got to do it like person-centred care, because if you don't, then it's abuse. (Participant 310)

The participants were also invited to define "good care". Most of them did not mention the phrase "human rights" in their definition. Nevertheless, there was often an alignment between a participant's definition of good care and their definition of and associations with human rights. Table 8.4 presents these associations and definitions, along with some examples:

Table 8.4 Participants' associations with human rights, human rights in care homes and definition of good care

Participant	Human rights general association	Definition of human rights in care homes	Definition of good care
308	People in war situations, where they should have basic human rights of food and shelter and warmth and be safe.	Residents should have basic human rights of freedom, choice, respect, food, safety, warmth and being treated as an individual.	I think good care has to be from basic level up. Treating that person as a complete individual.
303	You have a right to be who you want to be.	Because every single resident you have has a right to do what they	To support them and... emotionally and physically.

		want, eat what they want and choose what they want to wear, and we're just there to support them.	
302	Caring, compassion, basically following the human rights.	Whatever the residents need and want comes first.	If you are kind and you have patience and you respect a person then it's good care.
316	My understanding of human rights is people who are victimised for their beliefs or anything like that that comes to mind.	Everyone has the right to be listened to, to live their life and be supported to live their life how they choose to, so I think it's very important in a care home setting that we listen to the people who are living here, as well as the people who work here, yes.	Making sure that everyone's safe, that we listen to them, we treat them with respect, dignity, so, understanding, they're kind, we help support them in whatever it is they want to do, we make sure they feel and they feel safe.
313	People being imprisoned for having different values to others. I tend to think that in human rights tend to think of people who are imprisoned just because they have a different faith to the place where they live.	I feel that they should live more freely in a care home.	A good care to me is putting that person first in everything you do. That person, making them feel they are valued and again giving respect and dignity, but always make sure you put that person first.
314	We should all have, we've all got rights, haven't we, we should all be able to talk amongst ourselves.	They should be included just the same as everybody else should be, just because they are in here doesn't mean we need to exclude them from everything else.	Providing good care is not having to rush, having enough staff on to be able to give them the best care.
317	I would say human rights is about people's individuality. Everybody is unique. Everybody's views will be different.	I mean without using the phrase human rights I think all we do here at this care home and across the whole organisation is actually about being person-centred, which is another phrase for human rights.	It's about understanding the person you are caring for, knowing the person you are caring for and delivering what they want as far as is possible and what they need in an individual way.

Referring to the role of human rights in shaping relationship between colleagues, one participant felt that human rights language could be abused by members of staff. This participant recognised that staff members have rights but did not believe that they should use the phrase "human rights" when asking for their rights. The following statement illustrates this:

> If a staff member came to me and said "You're going into my human rights because actually I only had 14 minutes for my tea break, not 15," I'd be like,"Really?" You know, that would annoy me. But if they came to me and said, "Actually, I need longer, I just cannot have my lunch and my cup of tea in 15 minutes," I'd go, "Yeah, that's fine, you're different to others, have five more minutes." So to me the phrasing of human rights could make me more difficult towards that somebody, maybe. (Participant 308)

8.3.7 Balancing rights, risks and the duty of care

The dilemma of how to balance residents' rights with risks and the duty of care was particularly prominent for this group of participants. One care worker explained:

> You have got to respect somebody's rights but you have also got to protect them even if it is protecting them from themselves almost… Once people are in residential care, we all have a duty to do what is best for a person. (Participant 318)

Care staff mentioned three types of risk: firstly, the risk to the safety of individual residents; secondly, the risk to other residents (this was rarely mentioned); and thirdly, the risk to staff. Whereas the risks to residents was mainly about protecting their physical integrity and well-being, the risk to staff related to reputational and professional harm and (sometimes) emotional and physical dangers. The participants considered that risks to residents and risks to staff were interlinked. They also spoke about the pathways they used to manage dilemmas between protecting residents' rights and the potential risks this posed. Relatives' wishes to keep their family members safe in the care home often caused additional difficulties relating to balancing rights and risks.

Most of the dilemmas that participants spoke about related to residents' mobility, eating, sexuality and personal hygiene. Staff were concerned that residents have the "right to make choices" in all these matters but that such choices could lead to residents falling and hurting themselves, getting lost, choking, sexually intimidating others or getting ill. The following are examples of dilemmas that care workers described:

Mobility:

> We used to have a lady here called Gaby [anonymised] and she was determined in her head that she could stand up walk around. We knew, if she tried, she would just fall and hurt herself. It's a balance of trying to give her like let her do what she wants and also keep her safety – safety comes first. (Participant 301)

> [One of our residents] wanted to go out across the road, we had a big shopping complex opposite. He said to me and I said, you know, I was frightened he would fall. I said, "I don't think you should go out there on your own." He was quite, "Well I can go shopping if I want." I sort of said to one of the care workers, "Can you sort of go with him and that." And then someone said to me, "You are keeping him a prisoner" and I said, "No I am not and I am not infringing his right to go out, but I am frightened he will fall over." (Participant 313)

Eating:

> Participant: In the morning for breakfast if a resident decides to have toast and they have quite a difficulty swallowing, we have to actually step in and say, "You can't have toast if you can't swallow properly", and that takes their human rights away, I think.
> Interviewer: How does that make you feel?
> Participant: Bad. They obviously want the toast and they know what they want and we can't give it to them. Especially when they get upset and say, "You're supposed to be care workers," we have to face a dilemma, but it's for their safety, really you do it. (Participant 303)

Sexuality:

> We had a resident who was sexually very active and he would watch porn loudly and touch female care staff. We had to make sure that everyone is safe but accommodate his needs too. (Participant 319)

Personal care:

> Suppose you know, say, you have somebody who didn't want to wash and that's that person right, if they don't want to wash and they wanna sit there and they wanna do that is that person's right? But it's also everyone else's right not to have to sit there with a person who is not washing and I think that's when you get into the what do you do? (Participant 314)

Many staff felt that rights-related risks to residents also posed risks to themselves and others. In this regard, participants most commonly mentioned professional and reputational risks, such as being

blamed or criticised by residents or their relatives. At times, they also mentioned physical and emotional risks, such as receiving abuse from residents.

Criticism from residents:

> It's a bit difficult, because some residents they might think that their human rights are not respected, because they think we might do something that is, we basically don't respect them like human rights, but it's about their mental health. We have to protect them as well. (Participant 302)

Abuse from residents:

> Even if sometimes we manage to take them out, they might have a strange reaction and they might want to go alone or shouting or fighting which is again bad for them. It's still not safe for them and for us either. We need to be really careful and to think how we can do that in the best way for them, but also for us. It is frustrating. It's hard. (Participant 302)

Criticism from relatives or other people:

> If they [care workers] were seen to be doing something against somebody's will, that can be assumed that that's abuse, but actually that person hasn't got capacity and actually it's in their best interests that they have a clean pad put on because they're wet and dirty and they're doing it for a wash because, actually, it would be abuse not to be doing it. (Participant 308)

> Participant: Families sometimes think you are a slave because you are a care worker. They have to respect us as well sometimes they shout at us.
> Interviewer: Why do you think they feel they can treat you like that?
> Participant: Because we are a care worker. They ask "Why is my dad not doing this? Why is my dad like that… you are not looking after them." But you can't stop them. Sometimes they want to wear a dressing gown because that's their comfort zone. We can't stop them. (Participant 315)

Participants commonly mentioned using mechanisms or tactics to manage such dilemmas. These mechanisms included the following: legal pathways, such as DoLS and risk assessment under mental capacity legislation; documenting events in detail; writing incident reports; holding "best interest"

meetings; and using tactics to either accommodate residents' choices or persuade them to change their mind. Some examples of these are presented below:

Tactics to persuade residents:

> I talk to the resident, like listen to what they have got to say. I try and explain to them what impact it will have on them. (Participant 301)

> Let them be themselves, let them make the decision, but actually, if they really need something and it's in their best interests, you can't force anybody, but you can encourage strongly; there's ways you can talk to people where you can get a positive outcome, and also on the same level there's ways you can talk to people. (Participant 308)

Tactics to accommodate residents' wishes:

> What we did, we arranged for somebody to go out with him, once a day, across to the shops. Let him get his newspaper and have a look around the shops and that. And then, once a week, what I did I actually asked one of the care workers to take him to the restaurant, across the road where he could have a meal out, because actually, because he had been brought into the care home, again, he thought his rights were being taken away from him and he said to me, "I am stuck in here like a prisoner". (Participant 313)

> One of our residents doesn't swallow properly and she fancied Weetabix (cereal) and she likes it with just a little bit of milk, but obviously, I went to my care staff and said she finds it hard swallowing but she has human rights to achieve what she wants to eat, and then we decided just to put extra milk in and put it in the microwave to soften it up a bit, but then we gave it to her and she still said, "Yeah, it tastes like Weetabix". (Participant 303)

Deprivation of Liberty Safeguards (DoLS):

> Mostly, residents want to get out. But you don't want to take a risk so we put DoLS in place straight away. In the risk assessment we have to say why he cannot go out because you are depriving them of their liberty to go out. It's about their safety first. (Participant 301)

I am making the right decision to help protect them. There is thing in place… called DoLS which will be a document to say that they can't go out. There is things in place to protect us as well. It's not just taking their human rights away. (Participant 306)

Mental capacity, risk assessments and "best interest" meetings:

Participant: Best interests. It's done through the Mental Capacity Act assessments.
Interviewer: Do you find those assessments useful?
Participant: Yeah. So we're identifying exactly what it is we're doing, either in their best interest or totally, because they haven't got capacity to consent. It is helpful. It protects people; protects them, protects staff. So it stops abuse, really.
(Participant 308)

Interviewer: So do you feel that the frameworks for where things are decided, like the MCA, is that helpful generally?
Participant: I think it's helpful, yeah, because you've got a legal document allowing you to help these people if they can't make the choice for themselves.
(Participant 308)

Documentation:

They've got their decision, yes, no, and if they don't want to, I'll try and persuade them, come back later, and if not, then you have to document it and... just making sure that any little bruise, any scratch, anything minor what you might think, "oh, it's nothing", you have to go and tell someone, you have to write it down because, I don't know, next week they could have a bruise that was this big to this big and you don't know what's happening. (Participant 310)

There was just a case that a resident didn't want to get dressed because he was masturbating. I told the care worker to document it for the family because you don't later want to hear from them "Why isn't he dressed?" (Participant 305)

Incident reports:

Once I had an incident with a resident and I was explaining it to her and then she called me a bully. And I was really annoyed and I apologised, "I am not a bully, I am just explaining it to you". But she said bully. I made an incident report and spoke to the family as well as I didn't want to be turned around by the family because they do

> sometimes. If something happened I would get the blame. So I just did an incident report. (Participant 305)

One care worker spoke extensively about the role of human rights in dilemmas. She felt strongly that human rights as a concept was the root cause of many of these dilemmas and that in reality it could have counter-productive effects on residents' rights. As an example, this participant mentioned a person who died from septic shock after choosing not to wash:

> I think that human rights is always one of those things that is exploited for the wrong reasons… It complicates things… I had a resident in the old home I worked for and he was very aggressive… He had cellulitis on his legs… he would never wash, he would urinate everywhere, he actually got gangrene and died through septic shock… But is it against his human rights, could you actually maybe got him, put him in a shower, showered him and he would have lived, do you know what I mean? (Participant 314)

This participant felt that human rights complicated care provision and made care workers fearful of taking decisions:

> Actually, all he needed was a wash. That and antibiotics. I always think of that firing squad where you have so many people so that nobody is accused of killing that person. It's the same thing. Nobody wants to take the responsibility to say "so we are going to do this because and having the guts to say we are going to do this" but pass it round. (Participant 314)

8.3.8 Principles of orientation

Most of the care workers mentioned principles that helped them to make decisions and navigate dilemmas about how to treat residents. Most of them mentioned that they thought about their own wishes, or the wishes of their parents or grandparents, in difficult situations:

> I wouldn't like personally if a care worker come to my grandad and says, "Right, you're having a wash" and stripped him off, and he didn't want that because he might have a routine what you don't know about, he might not feel comfortable with a woman, or a male… If they didn't have their rights, then what have you got to live for? You're entitled to your rights. (Participant 310)

> I always treat people how I would want to be treated myself and with people who live here, especially, even more so because I think of my own grandparents… wherever they were living, how would I like people to be with them. (Participant 318)

> When I am at work, I imagine it being my mum or dad… I sort of look at them and think, "How would I want my mum and dad treated?" I kind of implement that into my work. It can be hard. It's very stressful... (Participant 307)

One participant felt that having a human rights tool to support care workers to deal with dilemmas could reassure inexperienced members of staff. The tool mentioned in this interview was the "FAIR approach" (Scottish Human Rights Commission, 2011 p. 5), which is a step-by-step guide to framing dilemmas in a human-rights-oriented way. FAIR stands for Facts of the dilemma, Approach already taken, Interests at stake and Rights at stake. The participant felt that a tool like this could provide useful guidance:

> For someone who's never had a dilemma, someone who's new to care, they've got to know what to do. They just feel, "oh, well, I don't know what to do", they might not be able to express themselves and go and tell someone… so I think that [a human-rights-based tool for decision-making]… would help because it's on a piece of paper… and I think that could really help in a meeting just to say, "Right, this is what you do". (Participant 310)

9 Perspectives of care home residents and relatives

Chapter 9 reports the findings of the interviews with care home residents and their relatives. This chapter is structured in the same way as the previous chapter: each participant group has its own section, with sub-sections that reflect the data-driven coding frameworks (see section 5.6).

9.1 Residents

The general demographic characteristics of this group (presented in Section 8.1) were based on personal data that was collected before the interviews. However, during the interviews, most of the residents volunteered more information about themselves. For example, half of them had chosen to move into a care home themselves; the other half said that they had been moved there against their wishes. The majority of the residents interviewed had a disability, used a wheelchair, or required support with getting in and out of bed, washing and dressing on a daily basis. The rest said that their social care needs were limited and that they could leave the care home unassisted if they wished. In general, the participants who had chosen to move into a care home did so after experiencing patches of ill health, from which they had since recovered. The residents' personal circumstances influenced their perspectives on human rights in care homes.

The interviews with participants in this group followed a semi-structured interview guide to extract perspectives on the potential role of human rights in a care home. However, most of the residents wished to share how they perceived their life in a care home and the other people who lived and worked in them. Therefore, Section 9.1 captures not only their perspectives on human rights but also what they chose to tell the researcher whilst talking about human rights. Presented first are the themes that emerged from residents' statements about other residents, themselves, their families and the care homes they were living in. Then, residents' definitions of and associations with human rights are reported, along with their perspectives on the potential role of human rights in care homes.

9.1.1 Residents' perceptions of their care homes

During the interviews, many participants commented on the quality of their care homes. Nearly all of them said that their care home was a "good" care home, without being prompted or asked. Their statements included the following:

> It's a very good care home. (Participant 208)

> I think this is the best there is. (Participant 206)

They're very, very good in this home. (Participant 203)

We're in a good place. (Participant 201)

The residents also mentioned good practice points in their care homes, some of which were reoccurring themes in many of the interviews. Table 9.1 summarises the most common comments.

Table 9.1 Residents' comments regarding the quality of their care homes

Topic	Comments	
Food	The food is good (Participant 206)	We sometimes have a moan about the food but, on the whole, it's quite good. We are allowed to put things forward for the menus, within reason. (Participant 202)
Feeling of safety	When I get back here, I feel safe. There is something to be said for it. (Participant 206)	
Availability of activities	They put me in the choir. I was in the choir and I enjoyed that, because I would enjoy singing, you know. (Participant 205) They do have activities, which I like. (Participant 207)	
Celebrating special events	I had a really nice birthday cake, and shared it all round the home, to everybody. It was made here. Chocolate, as well. (Participant 209)	
Contact to people outside the home other than family or friends	We have people coming in from outside. We have discussions, talks, keep fit, yoga, quite a lot of things going on. (Participant 202)	

9.1.2 Residents' perceptions of other residents

All the participants spoke about their perceptions of other residents, themselves, care workers and relatives in the context of care homes without the researcher intentionally prompting them to do so. These four categories were often, but not always, interlinked. For clarity, each category is reported on separately.

Many of the participants spoke about fellow residents with dementia or other cognitive impairments. They commonly expressed negative emotions towards these residents. They felt that they demanded too much staff time, did not respect privacy, were violent or could not communicate in a meaningful way:

> There is a chap who is, he's a little bit dementia'd. I always know him going by because he walks with a shuffling walk. Sometimes he comes in here [the resident's room]. The last time he came in, he looked at me and he said, "This is not right". I said, "No, not right". "Yes", he said, "I will go out there and walk down that way". Off he toddled. Waste of time trying to shout to a chap like that. (Participant 208)

> There is really old old people… they don't know what they are doing half of them most of the time and that gets me sometimes… I don't mix in the lounge with them, because it depresses me. I see them all there and they go in there and they fall asleep… I think they think they are the only ones there… They are calling the carers, "nurse, nurse, nurse", whereas they don't understand that they have got lots and lots of people to sort out, look after. I think it happens as you get older. (Participant 206)

> It's sad, because at the moment, touch wood, I've got my faculties, but I see some of them here, they're never treated rough or anything, but I just think, it's so sad, they just don't know… Because some, they go, "Oh, no, that hurt me", and you don't know really if it's true or what, do you? Because you don't know... they might say, "Oh, he pushed me", or "she pushed me, and it hurt me", and things like that. Well, what proof have you got? (Participant 210)

Other participants felt that "old" people or people with cognitive impairments needed protection or caring relationships. Some participants felt that this was the purpose of a "good" care home:

> There's some little old ladies in here and all they want is for you to put your arm on their shoulder, really, and ask them how they are, and that's all they want. They feel good then. They'll probably go to bed and think, "Well, somebody cares for me". I'm not saying they don't get that feeling; they probably do, but I think it could be shown a lot more, you know. (Participant 205)

One participant mentioned the need for residents to respect each other, especially when it comes to socialising:

> Some people don't want to mix, some people want to be on their own, which you have to respect. (Participant 201)

9.1.3 Residents' perceptions of themselves

The participants' perceptions of themselves in the care home were influenced by their perceived level of physical ability. The residents who did not have a physical impairment felt that their experience of being in a care home was different from the experiences of residents who did have a physical or cognitive impairment. They felt that this was because they could be independent, choose when to leave the care home and decide what to do with their time:

> We're fairly okay physically, aren't we? So it's a different... Yes, we're in a good place, which is important. We're able to be more independent, and we can go out and spend time out shopping or go for walks. We're not having to stay in. (Participant 202)

> I go out quite a lot, because I can come and go as I like, you see. It's just like having a flat, really. It's great. (Participant 206)

Two residents, who were both in their eighties and did not consider themselves to have permanent physical impairments (although one was in a wheelchair indefinitely), felt that they were "too young" to be in a care home. One of them implied that they felt guilty about having chosen to move into one:

> Participant: I suppose, by rights, I shouldn't be in a care home. But having said that, if I hadn't got anyone to look after me at home, what do I do?
> Interviewer: Help me understand why you think that you might not have the right to be in a care home.
> Participant: I think I am younger. I am 83, nearly 84. I have got all my faculties and I can walk… I think I can look after myself. I don't need to have anything done to me... It's just that I need the company and knowing that I have got care if I want it. That is why I am better coming at this age, so I know that as I get older and if I do get confused and things like that, it won't be so strange to me. (Participant 206)

The other participant (aged 85) was about to move out of the care home into a retirement village. This had reportedly been decided by the local authority that funded the resident's care. This participant regretted having to move. The participant justified the move by referring to their age:

> That was another thing they [the local authority] said I was really too young. I haven't got anything wrong with me, you know, where some of them are with dementia. It is very difficult. They [residents with dementia] are saying things that they are not really right, you know what I mean without sounding nasty. I am too young to be in here. (Participant 207)

Some participants, who were unable to get out of bed unaided, felt that they needed protection:

> I am badly well, I can't walk. I can't be much more incapacitated. I have only got half of my leg. I need protection. (Participant 208)

Others described their frustration with their perceived loss of agency and the fact that they need people to help them with everyday tasks:

> They [care workers] use a hoist to get me into bed because my knees don't hold up, and then having 12 hours laying there, I find – most of which I'm awake – I find it very frustrating. Frustrating is the wrong word: depressing. (Participant 203)

9.1.4 Residents' perceptions of care home staff

All the participants spoke about the staff and care home managers who worked in their respective care homes. They commented on the quality of care that the care workers were providing. Usually, they linked quality of care to attentiveness and work ethos. About half of the participants felt that care workers were attentive enough to their needs:

> I have never, right from the personal care and food and that, I have never had anything to complain about. Never. Never. When I am downstairs, sitting in a chair, because I can't get out, I will say to them... when I would like to go back to my room. They are always ready for me. (Participant 208)

> Participant: The individual carers, they're very, very good in this home, very good indeed… They will give 101 percent...
> Interviewer: So what do they do that you find very good? Is there something that you really appreciate about them?
> Participant: It's very difficult to say, but they always go the extra mile… Most or nearly all of them do it with a smile; one or two are not being so positive. (Participant 203)

The other half of the participants felt that care workers did not spend enough time with residents, failing to meet their emotional needs. Often, their statements also included references to workload and knowing that staff have a lot to do. Some participants commented on the care workers' general attitude and work ethos, which they occasionally linked to the worker's ethnic background. The following statements report some of the critical comments made about care workers:

> They [referring to care workers] just wash you and feed you and do whatever and that's it. Then you're left. Especially me, because I don't get up; can't get up. (Participant 209)

> They do what they can. They are so short staffed, you see that they can't do the things they want to do, really. (Participant 207)

> Participant: I'd like them [care workers] sometimes to be a little bit more interested, but then they don't have time; they have such a lot to do. You can't blame them or [name of care home manager] or anybody.
> Interviewer: What would you like them to be more interested in?
> Participant: Me. (Participant 205)

> Filipinos, they are superior to the English girls; they work harder. Not all. We've got some very good English girls as well, but there are some that have come that haven't stayed, that haven't really worked as hard as they perhaps should. (Participant 201)

About half of the residents also commented on their care home managers. They all felt that the managers were attentive to their needs and encouraged them to be active and make their voices heard:

> We're encouraged here to put our views and also to choose what we want to do – within reason, obviously – but, you know, [name of care home manager] is a very good manager. (Participant 201)

> That wheelchair is a special, it was bought by the manager for me. (Participant 210)

> [Name of care home manager] is a wonderful manager, she really is. She gets you going, you know. (Participant 206)

9.1.5 Residents' relationships with relatives

The interviews with residents highlighted the importance of family relationships in their perceptions of care home life. They all spoke about their families or other people outside the care home community who do things for them. Most of the participants had experienced losses in their close family circle, some of them multiple times. In most cases, the participant's spouse had passed away. At least three participants had lost adult children as well as their spouses.

Some participants spoke about other traumatic experiences with their families. At least two residents were not welcome to see or contact their spouse or children, and at least one felt that their adult child was not visiting often enough. One resident implied loss of agency, as the

participant's spouse had "put" them in the care home. A few of these participants spoke about the care home community now being their family. Below are some of the statements:

> I fell out with my son... I was going to be at his for Christmas. He came up and said, "You won't be welcome Christmas, Mum". I thought "Well," and I do get that upset about not going to his for Christmas. I thought, "Oh well, that is okay. I have made friends here. I will spend Christmas here." It was a wonderful Christmas… One of the best Christmases for a while since I lost my husband. (Participant 206)

> My daughter only lives down the road and I haven't seen her for four weeks now. So I shall have a go at her when she gets here. (Participant 205)

> I went through a whole period at home of falling because of my knees and I became too much of a strain on my wife, so that's why I was put in here. (Participant 203)

Other participants expressed feeling gratitude towards their family members or friends for supporting them. Most often, these family members were daughters-in-law, sons-in-law or grandchildren:

> My daughter-in-law is very, very good, but when my son died, that's her husband, she's got her big house to look after and things like that, and me and all. She does most of the paperwork for me. I can't ask any more of her, really, than what she's doing. She's got arthritis, osteoarthritis, very painful. Although I've got that wheelchair, she brought it for me yesterday, she can't push it with me in because of my weight… My grandson, he lives in Scandinavia so I can't see him very often, but he does phone regular and he also comes to see me about two or three times a year, they come over. (Participant 205)

9.1.6 Human rights: definitions

Of the ten participants in this group, four claimed that they didn't know anything about human rights. However, they all either provided a definition of human rights or associated it with a range of concepts. Some participants adopted law-based definitions, mentioning the HRA. This contrasted with the assumption made by some care home managers that residents do not have such knowledge:

> [Tony] Blair incorporated the human rights legislation into British law from the common... from the European Union, and it was really instituted after the war to prevent all the things that happened in mainland Europe before the war, and which I'm old enough to know. (Participant 203)

> There is a body somewhere further along the line and you can end up going to those people and they will say, under the Human Rights Act you should do what they are asking or they shouldn't be asking you to do it. (Participant 208)

Others suggested that human rights are universal and are grounded in dignity and fairness:

> Interviewer: Do you think human rights should matter in care homes?
> Participant: Yes, of course it should, because we don't stop being human beings, just because we're in here. In fact, we're waiting to die and we should have a bit of dignity. (Participant 209)

9.1.7 Human rights: associations

The participants made associations between human rights and concepts such as freedom, equality and fairness. All the participants, even those who said they knew nothing about human rights, showed some understanding:

Freedom and fairness:

> Human rights… it relates to a person's freedom. (Participant 201)

> Interviewer: Do you relate human rights to something like more negative or something positive or neutral?
> Participant: I am positive about it all, really. As I say, I've got my own freedom. I just don't know... I can't put a downer on any of it [referring to life in the care home]. (Participant 206)

> I do like fairness for people. I think everybody's got a right to be heard, so I'm all for human rights. (Participant 202)

Immigration:

Two participants spoke about immigration and refugees. One of them felt particularly strongly that human rights were abused in this context:

> I feel strongly on this, that the thing [human rights] is being misused by the law in this country. I'm talking, of course, refugees, call them what you will, other people, countries, break the law, seriously break the law and then they teach human rights to prevent their being deported. It makes me very angry indeed. (Participant, 203)

The other participant drew links to immigration and "killings", possibly suggesting that migrants' human rights are being violated:

> Participant: Human rights. Hasn't been much of that lately, has there?
> Interviewer: Can you expand?
> Participant: All the immigration... and emigration... and migration... and all the killings. I hope that it will change, but I don't suppose it will. (Participant 209)

Other residents associated the concept of human rights with subjects from the past or with issues in other countries. One participant mentioned the former apartheid regime in South Africa, and another spoke of the treatment of children in Romanian orphanages since the end of World War II:

Issues abroad and human rights violations from the past:

> Participant: Human rights is about, you don't like to feel that people are imprisoned for their views. I've actually lived in South Africa, during apartheid time, so I saw human rights in a different aspect.
> Interviewer: Would you like to explain?
> Participant: Because of the colour bar… it was a bit of a shock to see how the human race was treated… there were a lot of British people that felt uncomfortable, but we had to respect what was happening in that country... otherwise we might have been in trouble, so you have to keep quiet. (Participant 201)

Government and safety:

One participant linked human rights with government and a lack of human rights. When invited to think about human rights in the context of a care home, this participant associated the concept with being "safe":

> Interviewer: What does it mean to you, human rights?
> Participant: I don't think we've got any human rights
> Interviewer: What makes you say that?
> Participant: I don't know. Because they always get their way in the end, anyway.

Interviewer: Who's they?

Participant: Government.

Interviewer: Do you feel human rights is something that's important to you here [in the care home]?

Participant: No. I think we're safe in here. (Participant 205)

However, many residents did consider human rights to be relevant in care homes. Most of the associations they made were related to how they as residents were treated:

Interviewer: I am going to speak to you about human rights and care homes; is that okay?

Participant: Like how they treat you here and that sort of thing? (Participant 210)

Some participants also mentioned the concepts of freedom, fairness and the right to be heard in a care home context:

It's something you don't think about the actual expression, human rights, you don't think of it, I don't think, connected with a home, but actually, now I've thought over it, it's very important… I do like fairness for people. I think everybody's got a right to be heard. (Participant 202)

9.1.8 The potential role of human rights in care homes

Some residents offered perspectives on the potential role of human rights in the care home. These were either law-oriented or care-practice-shaping.

9.1.8a Law-oriented perspective: "no role"

One resident took a law-oriented perspective of human rights, defining it as a potential legal remedy for a violation of human rights. However, he implied that legal avenues other than human rights law could be used in cases of mistreatment in care homes. He perceived no direct role for human rights law in care homes. The following dialogue illustrates this perspective:

Interviewer: When you think about human rights in care homes, do you think it is important for your life?

Participant: Frankly, no… If I was mistreated by someone I'd have recourse to the law, I wouldn't hesitate because my daughter and my granddaughter are about to be solicitors, so if anything like that happened, I would have recourse to the law. One reads these stories in the press, the headlines in the [*Daily*] *Telegraph* last week

about care homes, it doesn't apply here. This one is well run and there's no question about it. As I said to you, as far as I'm concerned, I wish I could be sure that I'm going to be got up at half past seven or eight every morning, but I'm not. That's hardly a human right.

Interviewer: So human rights for you is something that comes in when there's abuse in a care home, so it doesn't apply here?

Participant: I don't think it does. I really do not think it does. (Participant 203)

This perspective could also be interpreted as a reactive one, in that human rights law is an avenue for legal redress in the case of perceived mistreatment. However, throughout the interview the participant remained ambiguous about this point.

9.1.8b Equal rights and care practice

Some participants took an equal rights perspective, considering that the purpose of human rights in care homes should be to ensure that all residents and staff are treated fairly. This perspective often overlapped with a care-practice-shaping one, including the idea that care home staff should treat residents in a fair and equal way:

Interviewer: What do human rights mean to you in a care home?

Participant: Well, that we're all treated fairly, and there's no difference made, I guess. (Participant 202)

Another participant spoke about the role of human rights in the relationship between care home staff and residents with dementia. This resident felt that staff should be patient, tolerant and sympathetic:

I'm very much against treating people badly and especially people who are weaker, because they can't retaliate... There's more and more cases now of dementia everywhere, people are living longer and some people, of course, have quite severe Alzheimer's as well, so anyone who cares for them needs a lot of patience, tolerance, needs to be really sympathetic. (Participant 201)

The participants also gave examples of what fair, equal and dignified treatment entailed in practice:

We're encouraged here to put our views and also to choose what we want to do – within reason. (Participant 201)

> We are encouraged to go to [care home manager's name] or one of the care workers if we've got a problem, and it can be sorted out. (Participant 202)

According to another participant, respecting their human rights meant having a care worker of their choice to have conversations with. To this participant, a care worker's skill in supporting residents emotionally was especially important:

> Interviewer: What would it entail for you, if you could think of a perfect care home?
> Participant: For each person to have time to spend on their own with a care worker of their choosing. (Participant 209)

9.1.8c Organisational ethos

One resident took an organisational perspective, suggesting that care home managers can choose to instil a human rights ethos in care workers:

> Interviewer: Do you think that human rights is something that's valuable and applies to people living in care homes?
> Participant: Depends on the ground rules. Depends on the person in charge of the care home, what he wants to instil into the care workers. (Participant 209)

9.2 Relatives

Eleven relatives of care home residents were interviewed. Most of them reported that their family member lived in a care home because they had dementia or were unable to look after themselves at home. The sections below report the themes that emerged from analysing the interviews using a data-driven coding framework. The first two sections describe how the relatives perceived older people and their relative's care home. Then, their definitions of and associations with human rights are reported. Similar to the other participant groups, this group held a range of perspectives on the potential role of human rights in care homes. The final section reports the perceived challenges in making those roles a reality.

9.2.1 Emotional journeys: relatives in a care home

Most of the relatives in this study felt compelled to explain and justify why they had "put" their relative in a care home. Many spoke of an emotional journey that led to making this decision, explaining that they could not look after their parents or relatives. The following statements illustrate this:

> There is no alternative. We had my mother living at home for eight months and we had a care worker looking after her in the nighttime and another one in the day time, and then I would go up and my sister would go up and my nephew would go up and a friend came round every couple of days. And after eight months it was just not working, a downward spiral… So you know we were trying to make the best out of the worst situation. And we tried. (Participant 402)

> You see, a care home to us is 24 hours help, but we couldn't give that. We ran ourselves ragged… and that was a horrendous decision but it had to be done because we have lives as well. (Participant 410)

Concerns about the safety of elderly parents, especially those with dementia, were common throughout the interviews with relatives. This thread is apparent in many of the statements in this section. Safety concerns had influenced children's decision to place a parent in the care home; they also shaped some relatives' perspectives on the quality of their family member's care home.

9.2.2 Older people: associations and perceptions

The participating relatives were not asked questions about their perceptions of older people or older age. However, statements expressing some of these perceptions were common. Some of these related to adult social care financing and "generational justice"; others were more about perceptions of older people *per se*.

One participant mentioned the financial climate and the state of social care in England, which they said put younger people at a disadvantage. The participant thus drew a link between social care financing and generational fairness:

> You gotta sell your property then as you know that's always on the news that people like you [name of interviewer] will lose everything because Mum and Dad will go into one of these places [referring to care homes]. Which is all wrong. (Participant 407)

Two participants – a married couple who were interviewed together – implied that older people are less able to adjust to new situations in life and that they may not be safe when doing the things they are used to doing. They were referring to tasks such as boiling a kettle or walking up and down the stairs:

> Older people are set in their ways. And some of the things your father was doing, he shouldn't have been doing because it was too dangerous. It was very difficult to

> speak to him and to make him realise that what he was doing was not the safest thing. (Participant 411)

Another participant shared the opinion that older people need to be managed differently from people in other age groups:

> Older people, it's just they are difficult to manage, but easier to manage, in a way. It takes a lot of energy and actually enthusiasm to give really, really good care, I think in terms of actually talking to people and really engaging with them and stuff, especially when it's like a busy day. (Participant 404)

One participant, speaking about human rights and older people, said that she believed that younger generations and older generations think differently about human rights. She implied that older people would not make their voices heard:

> Participant: I think the younger generation perhaps would have more of a voice about human rights or know more about their human rights. Perhaps older people wouldn't think about it in the same way. I don't know.
> Interviewer: Could you help me understand why you think that maybe older people don't—
> Participant: I don't know. I just wonder whether it's a generation thing. Older people, certainly my father's generation, people who just get on with life and have not perhaps. Him, personally, would not really think about that at all. It's not because he's not well, weird or anything, he just wouldn't consider it. (Participant 401)

One participant shared her perception of life with dementia. This participant felt that some people with dementia could not have a high quality of life:

> My mother, the quality of my mother's life, I question that. It's nothing to do with the care home. It's about her having dementia. It makes me question myself about quality versus quantity of life. You know what I mean? I just think in her position — you know, she doesn't want to be around, really. It's a bit sort of ironic really, it's the right to her life, which she doesn't want a life. She doesn't have quality of life. (Participant 404)

9.2.3 Human rights: definitions and associations

Two relatives said that they did not know anything about human rights. However, similar to the situation in other groups, they both shared perspectives that demonstrated an understanding of human rights. Some interview participants gave definitions of human rights, whilst others made associations between human rights and concepts and actions.

When defining human rights, several participants mentioned the HRA. However, unlike the other groups, not all the relatives thought that human rights applied universally. Some felt that people with cognitive impairments were no longer entitled to human rights. The following statement illustrates this:

> The thing that comes to mind is the right to freedom. She [the participant's relative with dementia, who lives in a care home] doesn't have her freedom. It's like for her own good... I suppose the other thing... is like, you know, the first points of Human Rights Acts, isn't it. It's like the right to life... Mum doesn't have mental capacity, in some ways she doesn't have the rights that she had before, because she needs to be kept safe. (Participant 404)

Another interview participant defined human rights by what they should enable people to do. However, in this definition, human rights are conditional on individuals being "safe":

> Human rights is about doing what you want, as long as you are safe.
> (Participant 410)

Two relatives said that human rights can be acquired by or bestowed on a person. They felt that human rights are often bestowed on "undeserving people such as criminals":

> What upsets me is that the person doing all the wrong this seem to have more human rights than the people who they are doing the thing... so I feel very strongly about it to make sure that the people getting the human rights is those who deserve them. (Participant 408)

One relative defined human rights by referring to principles. For this participant, human rights were not conditional but universal:

> Human rights? I think fairness, equality, justice and dignity... These are people, aren't they [referring to the care home residents]? And you got to treat those people with dignity whether they have dementia or not. (Participant 406)

The participants were invited to share what comes to mind when hearing the phrase “human rights”. Some of them associated the concept with negative words or events abroad (or both). These included “human rights abuses” and “things that should not be happening”:

> When I think of human rights, I probably think of human rights abuses, the term itself makes me think of human rights abuses. People who have been imprisoned or tortured, you know, stuff like that, that is what it makes me think of. (Participant 404)

> [I think of things] that shouldn’t be happening. (Participant 401)

Another participant made a link between human rights and lack of voice:

> Human rights is so lacking in some countries, that they haven’t got a voice. (Participant 405)

9.2.4 Human rights and care homes

Before offering a perspective on the potential role of human rights in care homes, many of the relatives expressed general views on how human rights and care homes are inter-related. Some thought that care homes and human rights were mutually exclusive, and that people lose their human rights when they enter a care home. This was seen as especially true for people who were moved into a care home against their will:

> You have people here by and large against their will. They don’t want to be here, so it is a form of being incarcerated. It is a humanitarian incarceration… It’s a jail for their own interest. (Participant 402)

> Placing someone in a care home can feel, can feel what, as if you are depriving them of their human rights. (Participant 404)

Almost all the participants mentioned how they felt about their relative’s care home. Often, this was discussed in relation to human rights in the care home. Nearly all of their comments were positive, with relatives saying how good the home was and how positive their family members were feeling about living in it:

> This is the only care home we have had dealings with. But they are all treated with respect, which is good and dignity, which is another thing, they haven’t lost that,

> which is what we all want, isn't it? It's pretty good, they are all kind… I would be saying that they have got human rights here. (Participant 407)

> I think it's all been positive. Dad has been very happy here. (Participant 401)

On the other hand, many of the relevant statements imply an association between human rights and mistreatment in care homes, or a lack of engagement with residents:

> I would be saying that they have got human rights here. If [name of resident] has ever not been happy with something than it's always sorted out, which isn't often. Or if we aren't happy with something. I mean that is human rights isn't it? (Participant 407)

> I haven't really thought about it [human rights] too much, because Dad's happy here. I haven't thought anything was happening that shouldn't be happening. I haven't had to question that at all. (Participant 401)

9.2.5 The potential role of human rights in care homes

The participants were invited to share their perspective on what role human rights could play in care homes for older people. Their responses revealed a wide range of perspectives and approaches.

9.2.5a "No role" safety-focused perspective

Two participants took the "no role" perspective: they felt that human rights and life in a care home were mutually exclusive, because the primary purpose of a care home is to keep residents safe. These relatives did not believe that human rights had any relevance for people living or working in care homes. One thought that issues inside care homes were management matters rather than human rights issues. The other believed that human rights had no practical purpose in a care home:

> [Participant had explained about lack of communication between herself and her relative's care workers]
> Interviewer: Do you feel that that could actually be a rights issue for you as well, for your family life with your mother being informed, or do you not think of it that way at all?
> Participant: I don't think of it that way, really. I think of it, don't think of it as a human rights issue. I think of it as a management issue. (Participant 404)

> Interviewer: So do you think that human rights is then something especially relevant here in the care home?

Participant: No… I don't. It's a theoretical discussion rather than a practical discussion. That matters. Because there is no alternative. (Participant 402)

9.2.5b Law-oriented: reactive perspective

Some participants took a legalistic, reactive perspective on the potential role of human rights. They felt that human rights only become relevant in care homes when there is a problem. In addition, they believed that for human rights to play a role, there needed to be advocates inside the care home:

Interviewer: Do you think that human rights could play a role for them [care homes] at all?
Participant: I don't know how that could have, unless you have got an advocate, how would that work? I don't know. I don't know how you could, could you have an advocate in each home. I don't know? (Participant 401)

9.2.5c Equal rights perspective

One participant expressed the view that one role for human rights in care homes could be to ensure that people are not discriminated against on any grounds, including an LGBTQ+ background:

If I go into a care home, how fairly will I be treated in terms of being discriminated against, because I am lesbian, for instance? (Participant 404)

9.2.5d Care- practice-shaping perspectives

Many relatives shared a normative care-practice-shaping perspective. They felt that the role of human rights should be to ensure that staff provide high-quality care to everyone in the care home. One participant in particular felt that care homes – their managers and care workers – need to know about human rights:

The care homes and staff, they have to start thinking about human rights whether they like it or not, because it is becoming more and more of a topic. I think it's important and I think it's good, because, you know, you shouldn't have to have worries like this. (Participant 404)

To define how care home staff should treat residents in line with human rights, the participants frequently referred to concepts. Some of these are presented below.

"Being treated with respect" and having choice

Some participants believed that care practice in line with human rights meant treating everyone with respect:

> Interviewer: When you think about human rights, what comes into your mind?
> Participant: Just that people are treated properly. I don't really know, I'm not really that up on everything, so just that they're treated with care and the right respect. That's how I want my mum to be treated, and to be given the choices, as well. (Participant 403)

One participant defined being treated with respect as having choices about their day:

> So you would hope that all homes are gonna respect people and care for them. All in the best safest way, but making sure the person is able to do the things they do like to do. And have the things they like so they can live a life that is, you know, as fulfilling as it can be under the circumstances. (Participant 401)

"Being listened to", "being cared for" and "being heard"

Other relatives defined care practice in line with human rights as listening to, caring for and hearing residents:

> That one to be listened to and obviously that one, the caring side, looking and hoping you are being listened to and cared about, really. (Participant 401)

> So that is someone being heard, when they make a request and tell someone how they want things to be, someone listens and does that. (Participant 411)

"Being treated as an individual" in a communal setting

The communal nature of a care home environment influenced some of the responses. Here, the relatives linked human rights and care with being treated as an individual:

> Interviewer: What do you think of when you hear the word "human rights"?
> Participant: The individual is catered for at any time amongst everybody. (Participant 406)

One participant also mentioned the principles of dignity, respect, choice and control and their significance in a care home environment. However, she did not link these principles to human rights and said that she had never thought about it in those terms:

> Participant: They do treat her with respect and dignity and that's my main thing. If she wasn't being treated with respect or dignity, I wouldn't be a happy bunny...
> Interviewer: Do you think of this in terms of human rights? Do you think that could be useful?
> Participant: I think it could be useful if we are thinking about it in those ways, yes. I have not really thought about it, to be honest. (Participant 404)

The same participant – who was concerned about her mother's safety and well-being – felt that principles related to human rights sometimes led to care workers not fulfilling their care tasks properly:

> In terms of choice… sometimes I feel that is used as an excuse, Mum having choice and control. A few times I have had to say, "Mum is a bit whiffy" and so that means a bit smelly. "You need to ensure that she has a bath and a shower on a regular basis." Sometimes they say, "She had chosen not to. We have to respect that choice." I have to say, "But look, she has been assessed as not having mental capacity. I am saying that she doesn't have the capability to say that." (Participant 404)

9.2.5e Care homes as "human-rights-enabling environments"

Some participants shared the view that care homes can be "human-rights-enabling" environments. They argued that the right kind of environment can ensure that residents who might have struggled in their own homes can lead self-directed lives:

> [The care home] gives them more freedom, their human rights than when they were at home. They might have been at home, but they were trapped. (Participant 410)

> I believe they should be able to live the way they want to live but I know that needs to be safe… But I think they have the right to do what they want and in the care home they are guided the way that best suits their needs. (Participant 411)

These participants felt that three factors make care homes human-rights-enabling. Firstly, care homes have the necessary facilities to cater for individual needs:

> And they have got more facilities here than where they lived, because they lived in the same bungalow for over sixty years and they hadn't updated it, the facilities were very poor, they haven't been able to have a bath. The facilities here are all

> geared to people who have difficulty having a bath, getting about, going to the toilet and they are warm. (Participant 410)

Secondly, there is a stable community of people and care workers who cater for residents' needs around the clock.

> It is the safety of the group. Because you have always got someone there… At home, there is just you. Here, you have a mix of people. She [referring to the relative in a care home] she knows a lot more than when she lived at home… Very social. (Participant 410)

Thirdly, care workers are available round the clock. According to the participants, this is not the case in the private home environment:

> People work shifts don't they, so you have people doing a shift and they go home and people are fresh on their shift, they are not tired because they are doing it all day and you get new faces. (Participant 411)

9.3 SUMMARY

This chapter is the second of two that presented the findings from the interviews with people living in, working in and visiting care homes. The findings of this chapter and Chapter 8 reveal that there are commonalities amongst and within the participant groups. Nonetheless, the groups have heterogeneous perceptions and views on human rights, especially in the context of care homes. Indeed, this study shows that there are multiple subjective perspectives on the potential role of human rights in care homes. This provides the basis for a typology of perspectives, which is discussed in Chapter 10.

10 Discussion: typology of perspectives on the potential role of human rights in care homes

This research contributes to the debate on the rights of older people in long-term care by exploring multiple perspectives on the potential role of human rights in care homes. The research considered the voices of people living in, working in and visiting care homes, in addition to the CQC as the regulator of care services in England. Further, it contributes towards a mutual understanding of good practice for respecting care home residents' right to privacy. The questions asked in this study for this purpose are summarised in Table 10.1.

Table 10.1 Overview of the research questions

Research questions
• What is the background to the CQC's human rights approach? • What is the CQC's explanation of their human rights approach to regulation and inspection? • What is the role and purpose of their human rights approach, according to it?
• How do people visiting, living and working in care homes understand the concept of human rights? • What role do participants think human rights play for care homes? • What role do participants think human rights *could* play for care homes?
• What is the evidence for good practice in protecting care home residents' right to privacy? (literature review) • What according to study participants is necessary to protect the right to privacy in a care home setting? • What, according to CQC inspection reports and other relevant documents, is "good" and "poor" privacy practice in care homes?

This chapter adds to the typology of perspectives (Chapter 6) by taking into consideration the findings (Chapters 7 to 9) and the wider contextual background of this thesis (Chapters 2 to 4). Section 10.1 summarises the contribution of this study to the typology of perspectives. The sub-types under each main perspective are discussed in depth in Section 10.3.

10.1 Contribution of this research to the typology of perspectives: an overview

An analysis of the academic literature on human rights and care homes for older people was presented in Chapter 6. This analysis revealed multiple perspectives on the topic, and an initial typology of perspectives on the potential role of human rights in care homes was proposed. The typology included the key characteristics and assumptions within these perspectives. The perspectives were grouped into four types: social, political and adult social care; law-oriented; normative context shaping; and whole-system. Each perspective took a distinct approach to the topic and included several sub-types. It was argued that authors tend to approach care homes as inherently risky places for residents' human rights, focusing on human rights as a tool to address perceived injustices and violations. In many sub perspectives, care home residents were seen as victims of human rights violations.

The findings of this study confirm the four overarching perspectives. Some participants approached the topic from wider point of view on adult social care policy, whilst others approached it from a legal, care practice or whole-system perspective. The sub-types identified in the literature analysis were shared by many of the research participants.

The findings of this study also add to the typology in some important ways. Firstly, participants held three radically different sub-perspectives: the "rights-enabling", the "no role': alternative legal avenue" and the "no role: safety focused" ones. The first of these sub-perspectives offers a positive new way to approach the potential role of human rights in care homes. It is rooted in the assumptions that older people in care homes are equal rightsholders and that care homes are not inherently risky places but are rights-enabling instead. The other two perspectives critically question the value (and, thus, the potential role) of human rights in care homes altogether: something that was not done in the academic literature analysed for this thesis. Table 10.2 summarises the typology of perspectives, including the three new sub-types.

Secondly, interpreting the participants' associations with care homes, human rights and older people made clear that human rights in care homes can be a highly emotive topic. Their responses to the topic are rooted in people's background, roles, relationships and perceptions of themselves and others. This may have important implications for anyone working with care homes and human rights (see section 10.2). Furthermore, many participants thought that respecting and protecting residents' human rights was a goal in itself; these participants did not consider human rights as an instrument to address perceived injustices. This has some interesting practical ramifications.

Thirdly, the interview data added substance and discussion points to each sub-type. These highlight the many complexities involved in making the potential role of human rights in care homes a reality.

Table 10.2 Typology of perspectives on the potential role of human rights in English care homes

Type of perspective	**Sub-perspective**	**Main approach to human rights**	**Conceptualisation of main duty-bearer**	**Frequent conceptualisation of care home resident**	**Success factors/stumbling blocks**
Social, political and adult social care	Anti-institutional advocacy	Legalistic/analytical Instrumental	Government	Victim of potentially harmful social structures	Policy priorities; social and political climate
Social, political and adult social care	Rights-enabling	Normative Protection of human rights goal in itself	Multi-level responsibility (Government, society, care home system)	Rightsholder in the care home	Rights-respecting care home culture, current regulatory framework
Law-oriented	No role	Legalistic/NA	Government	Legal subject	Not applicable
Law-oriented	Violation-based reactive	Legalistic Instrumental	Care homes	Victim of human rights violations perpetrated in care homes	Availability and access to advocacy and legal aid services
Normative context shaping	No role safety-focused	Normative	Government	Stripped of human rights	Not applicable
Normative context shaping	Care-practice-shaping	Normative Protection of human rights goal in itself	Care worker	Rightsholder in the care home	Care home cultures and "ingrained care practice"; Issues of awareness around human rights

Normative context shaping	Equal rights	Normative/legalistic Protection of human rights goal in itself	Government	Rightsholder/citizen but living in "different context" from others	Policies and processes in place; Understanding of what it means in practice to have "equal rights"
Normative context shaping	Issue-based	Normative Protection of human rights goal in itself/instrumental	Care workers	Victim of human rights abuse	Specification of implications
Whole system	Whole system	Legal/normative/analytical Protection of human rights goal in itself	Multi-level	Rightsholder amongst other rightsholders	Lack of flexible thinking amongst duty-bearers, lack of recognition of duties amongst duty-bearers

10.2 Human rights, care homes and older care home residents: definition and associations

For the purpose of this thesis, human rights are defined as the rights and freedoms contained in the Bill of Human Rights belonging to all human beings (see Chapter 1). They can be understood as moral and legal entitlements; individuals are the rightsholders and governments are the main duty-bearers (Donnelly, 2013). There is a link between human rights and grounding values, such as equality, dignity, freedom and autonomy. Indeed, some have argued that in England such principles could be helpful in speaking about human rights (see Chapter 2). This reflects research which suggests that the concept is perceived negatively by some sections of the English population (Equality and Human Rights Commission, 2018a).

The findings of this study (Chapters 7 to 9) showed that in general, participants also defined human rights as *equal entitlements of all human beings, irrespective of their age or physical characteristics*. Even those who felt unable to comment on the topic implied such a definition in their statements. The few participants who thought that people with cognitive impairments in care homes were no longer holders of human rights still defined the concept by mentioning the HRA. This suggests that the participants had at least a basic theoretical understanding of one of the concept's core characteristics. This is a solid foundation for exploring perspectives on the potential role of human rights in care homes.

The interviews were analysed for definitions of human rights: the direct meaning of the concept as defined by the participants. They were also analysed for associations: the explicit or implicit connections that people made between human rights and issues or other concepts whilst speaking about the topic. Indeed, by drawing out and interpreting common associations provided by the participants, it became clear that human rights in general and in relation to care homes do evoke many negative associations – and potentially negative emotions. Negative associations here include not only abuses of human rights but also situations, contexts or topics that can be linked to human rights not being protected or that are inherently risky for human rights. Negative emotions include sadness, anger, frustration and fear, amongst others. A recent report by the Equality and Human Rights Commission (2018a p. 7) argued that a perceived lack of knowledge regarding human rights can lead to negative views. However, the connection between negative associations and this perceived lack of knowledge was not verified in this research.

Positive associations, on the other hand, are links with situations, contexts or topics that can be related to protecting human rights. Figure 10.1 summarises many of the participants' associations between human rights, themes (bigger bubbles) and related topics or concepts (smaller bubbles). In a discussion on the common associations between human rights and care homes, it is useful to

highlight participants' common associations regarding care homes in general and older care home residents. As described in Chapter 2, a starting point for the international debate on human rights and older people is to combat ageism, and care homes are often considered inherently risky places for older people's human rights. Figure 10.2 summarises the associations that participants made with care homes (introduced in Chapters 7 to 9), which are overwhelmingly negative. Figure 10.3 summarises participants' associations with older care home residents, some of which could be considered ageist if appropriate analytical tools were applied.

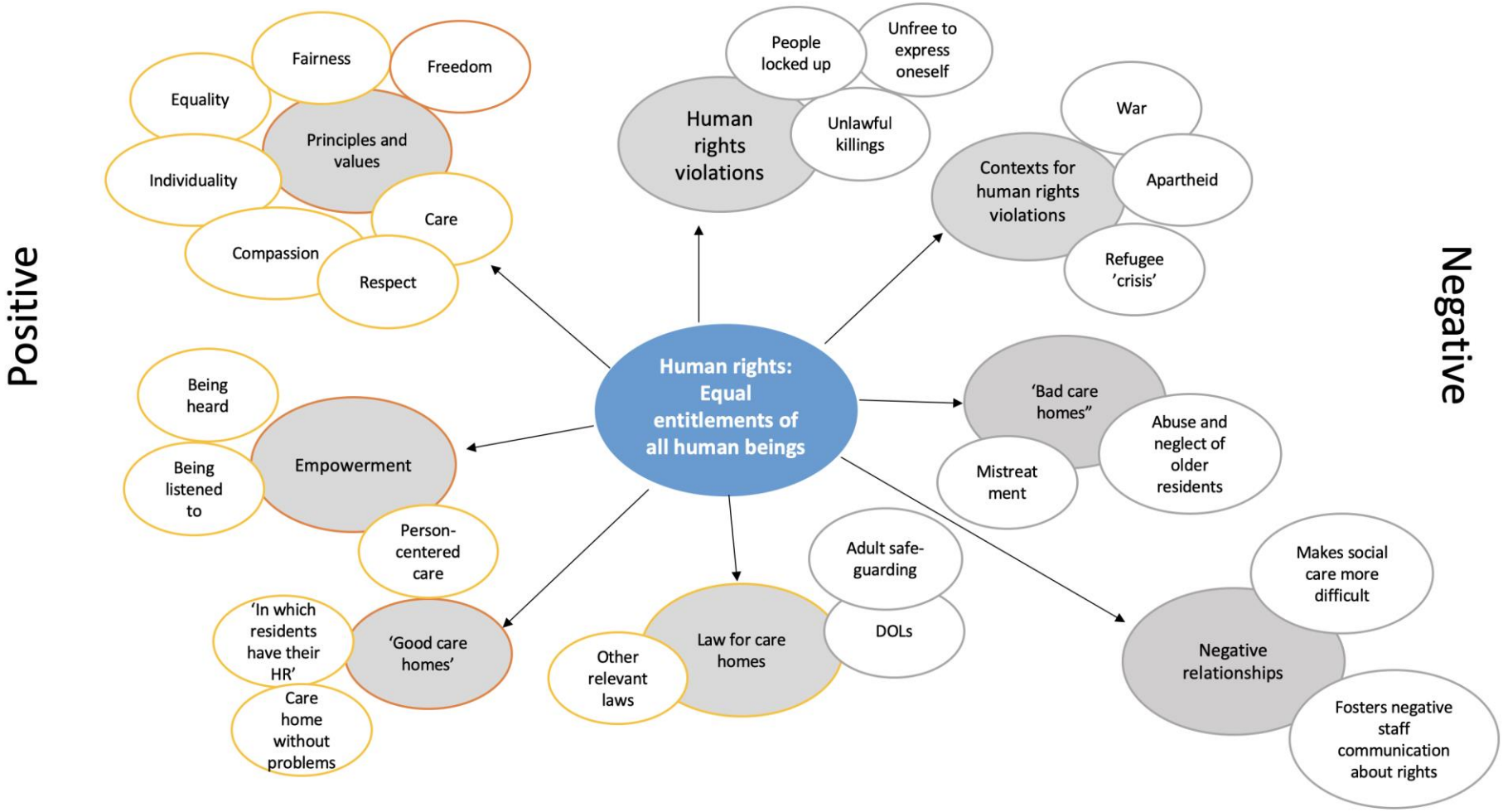


Figure 10.1 Study participants' associations with human rights

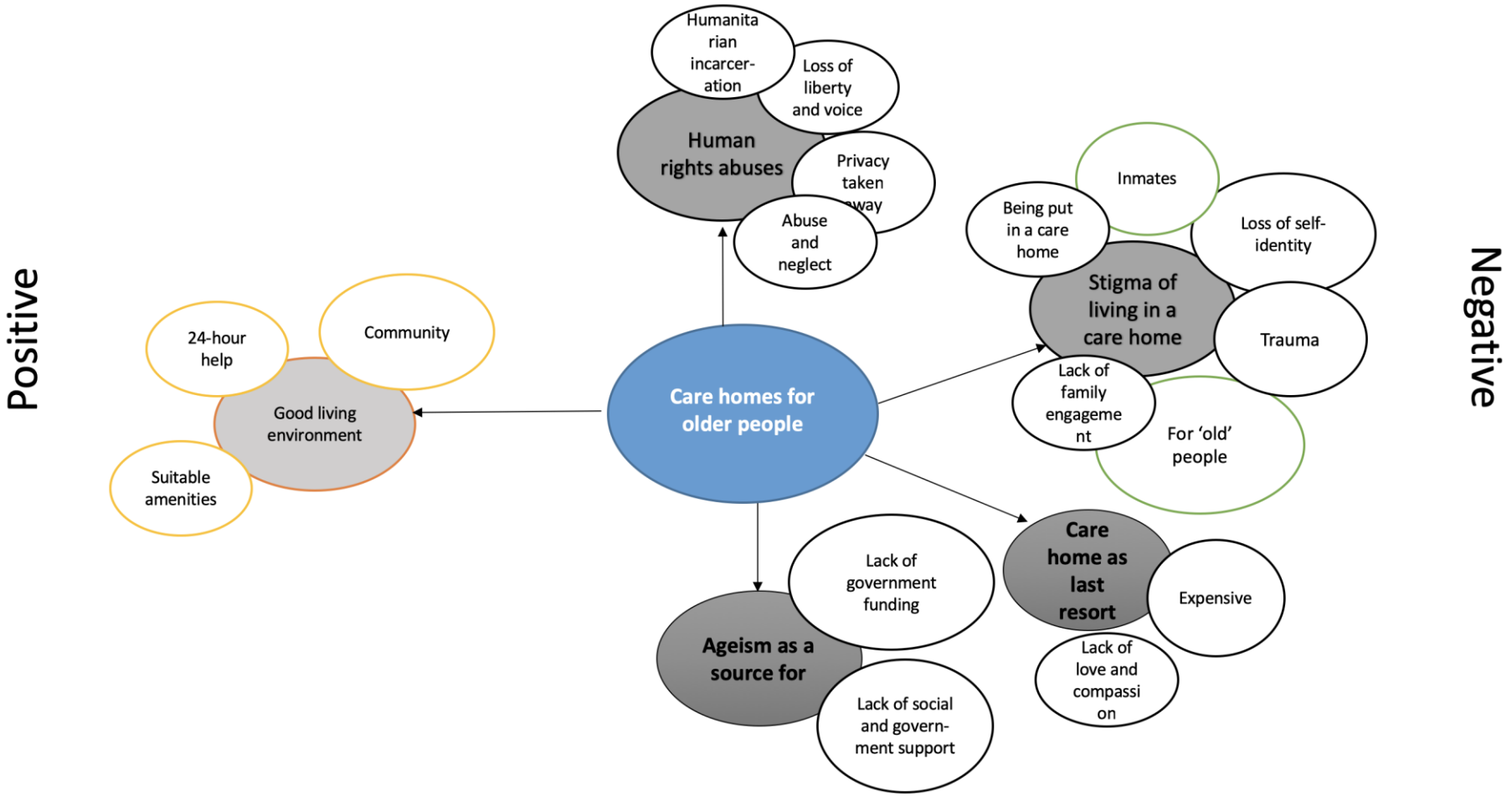


Figure 10.2 Study participants' associations with care homes

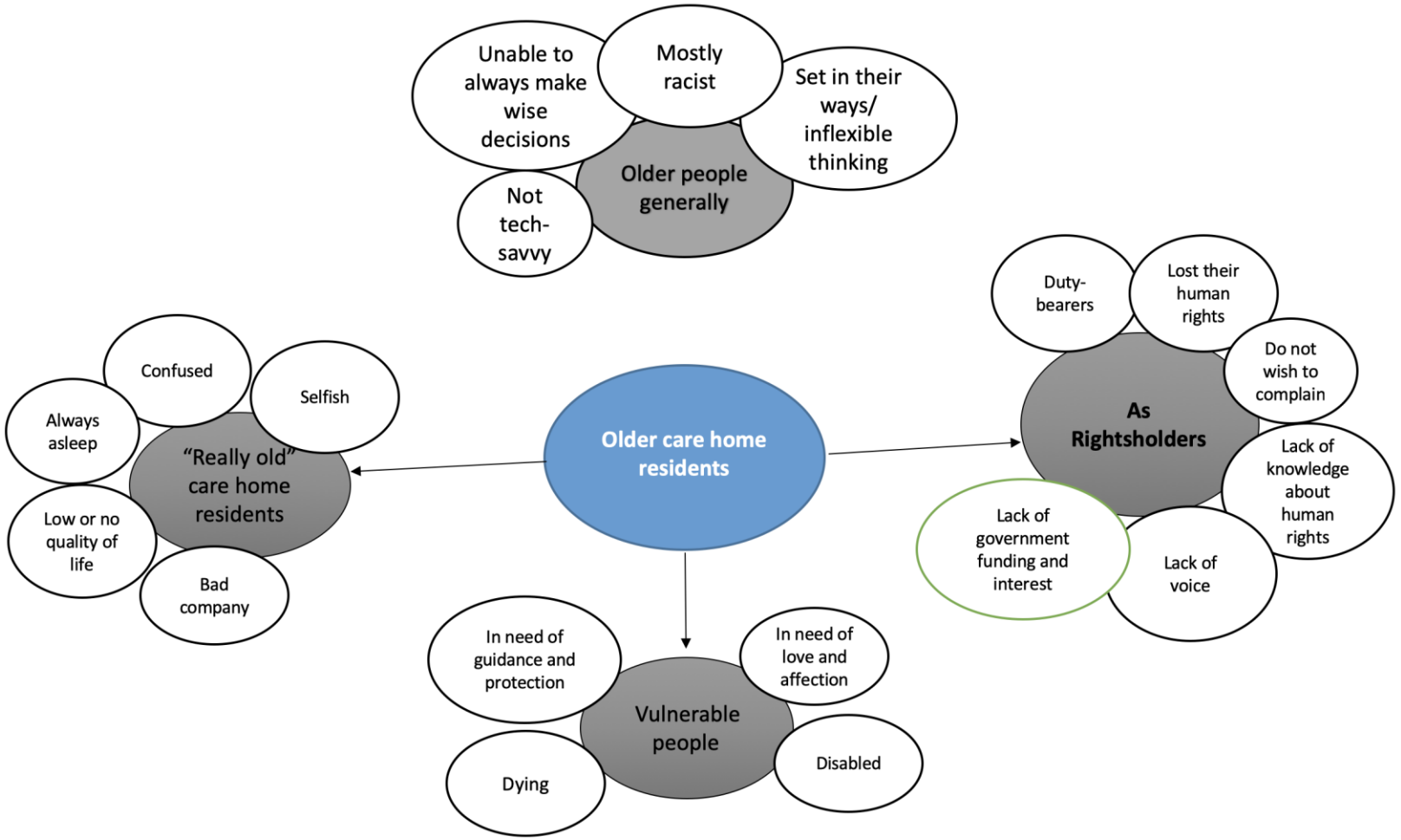


Figure 10.3 Study participants' associations with older people and older care home residents

10.2.1 Negative associations between human rights and care homes

The participants associated human rights in general with abuse and violations, such as people being imprisoned, being killed or having their freedom of expression curtailed. At times, these were mentioned in connection to precarious contexts for human rights, such as war or apartheid. Despite the fact that some participants made a link between human rights and issues "abroad" outside their own contexts, most of them also perceived these rights as relevant to care homes for older people.

Figure 10.1 suggests that associations between care homes and human rights were often negative and sometimes triggered negative emotional responses. Across the participant groups, people's reaction to the topic suggested that in the context of care homes they frequently link human rights with "bad" care homes; namely, those in which residents are abused or mistreated. In many of the interviews, the participants emphasised that their care home was a "good" care home, in which there were "no problems" and nothing to complain about. Residents, their relatives and the CQC experts also referred to care home managers and care workers, either mentioning how good care home staff were or commenting on their perception of (poor) staff performance. Taking this into consideration, participants at times appeared to be afraid to comment badly on their care home but felt more comfortable with being critical of care workers. On the other hand, some relatives and care workers showed emotional responses; for example, a few cried during the interviews and mentioned how difficult the topic was for them emotionally.

Some participants made a link between human rights and the law or legal instruments, such as the HRA or even DoLS. Often, these references were made in connection with abuses of human rights. DoLS in particular were considered as instruments that can justify limiting a resident's right to liberty, which indicates an awareness of how serious it is to deprive someone of their liberty from a human rights standpoint. However, the law was not always perceived in a negative way. Some participants acknowledged that human rights are the foundation of many laws and regulations that are relevant to managing and working in a care home, and that those laws gave them some guidance on how to tackle issues related to human rights.

Occasionally, participants also associated human rights with interactions between people in care homes, especially between members of staff and between care workers and residents. As such, some connected human rights with "counter-productive communication" between staff in care homes who could be encouraged to adopt a language of entitlement and residents, who disagree with the care workers.

The negative associations between care homes and human rights could have several roots. Firstly, human rights language is often used when governments are perceived to fail in their responsibility to protect people's human rights (see Chapter 2). The media picks up on abuses of human rights, and rights rhetoric may be seen to further agendas to curb perceived injustices (Nickel, 2007). It could be argued that human rights language tends to be "negatively" connotated, and those connotations could translate into care home contexts. This transfer may be facilitated by an acknowledgement by many participants that care home managers and care workers could be "bearers of human rights obligations" – and, thus, potential violators of residents' and sometimes care workers' human rights. In the interviews, some people mentioned the government's failure to discharge its duties to protect residents' human rights. However, many participants embraced the idea of care home staff as duty-bearers, drawing the link either expressly or impliedly. Care home managers were aware of their legal responsibilities under laws that are relevant to human rights and under the CQC's approach.

The rather negative image of care homes in English society has been mentioned several times in this thesis. This also became apparent in many of the interviews, as care homes were more frequently associated with negative topics and concepts (such as human rights abuses) than with positive ones (see Figure 11.2). Care home managers and relatives, and sometimes residents, viewed care homes as places where there are inherent risks to human rights. They put forward the idea of care homes as a last resort for older people. Very few participants drew more positive links between human rights and care homes, expressing the opinion that care homes can be rights-enabling. This is discussed in more detail in section 11.2. However, as became apparent in the literature review (Chapter 6), many academics have adopted human rights in order to highlight issues or problems in care homes, which may have reinforced negative stereotypes of care homes. This phenomenon, together with the acceptance of care home workers' rights-related duties and the negative connotations of human rights language, has manifested itself in the minds of many participants in this study.

Some of the academic literature on human rights and care homes approaches older care home residents as potential victims who are "vulnerable" to abuse and mistreatment. This, along with the international movement for older people's human rights (see Chapter 2), makes human rights especially relevant. The problem of widespread ageism and its possible effects is considered one of the main drivers of this debate. Social care in care homes has also played an important part in the discussion, as ageism has been linked with human rights violations in care homes. This study's findings on the perception of older care home residents suggest that at least some participants

share the view that residents are “vulnerable” and are sometimes unable to make “wise” decisions or stay safe because of their physical condition. This may be another cause of the many negative associations between care homes and human rights, especially between human rights and the abuse, mistreatment or neglect of residents. Despite the widespread acknowledgement in this study of older residents as rightsholders, there was a broad perception that residents are unaware of human rights, lack voice and do not want to complain. The participants implied that this makes residents more prone to becoming “silent” victims of human rights violations in care homes.

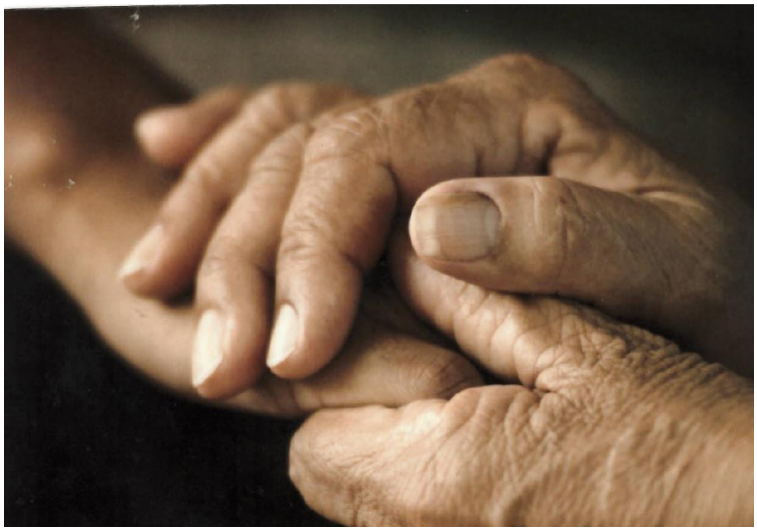
Chapter 2 briefly highlighted the “ethics of care” debate, which often criticises the focus of human rights rhetoric on individual rights at the expense of acknowledging human dependency, relationships and the human need for care at several stages of life (e.g. Lloyd, 2004). In line with some of that thinking, some participants also suggested that human rights can be counter-productive to providing the compassionate care required by people with social care needs and can complicate relationships inside care homes.

10.2.2 Human rights and values

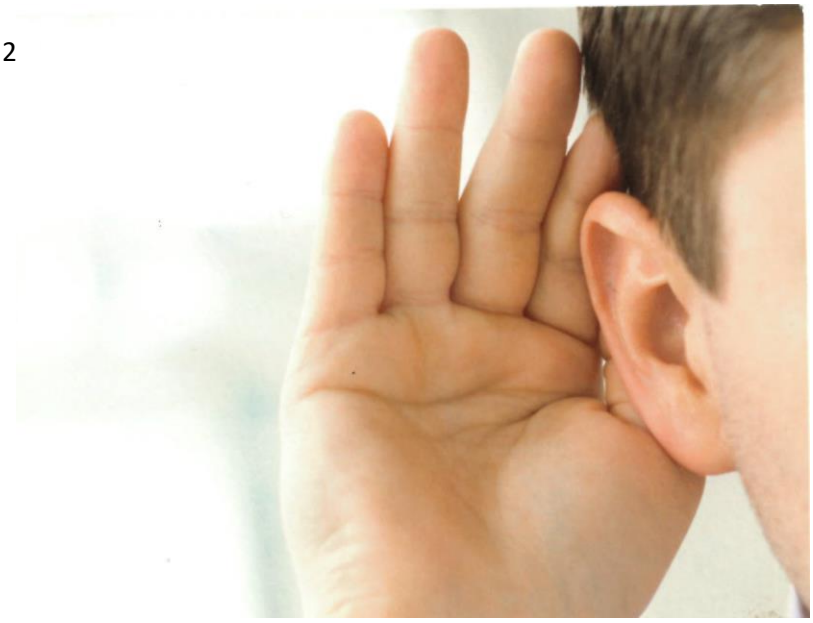
The interview participants often associated human rights with principles such as freedom, fairness, equality and empowerment, which may be considered as grounding values for human rights (see Chapter 2). In many instances, empowerment could be interpreted to mean choice and control (autonomy). Such associations, and some of the negative ones, may have been triggered by the method of using images to gain access to potentially abstract topics at the beginning of the interview (see Chapter 5). Pictures 10.1, 10.2, 10.3 and 10.4 show the most commonly chosen images in the interviews. However, the participants decided which image to choose and made associations between it and human rights without being prompted by the interviewer.

Picture 10.1

(copyright for this and the following three images: University of West of Scotland)



Picture 10.2



Picture 10.3

Picture 10.4

For some participants, the purpose of human rights was to protect one or more of these values. They frequently related this to residents in care homes, whom they believed should, for example, also be treated fairly and equally. Some participants translated these values into their own experiences and the meaning of those values to them. For example, the concept of freedom was often mentioned by residents, some of whom expressed their appreciation for being able to come and go freely and do as they wish in their personal space in their care home. Consequently, those residents considered their care homes to be good. The possibility of not being able to have this freedom in the future due to physical conditions that would make them frailer triggered negative emotional responses. This may be a psychological explanation for residents' negative stereotyping of other residents with advanced physical and cognitive impairments (see Figure 10.3), who were sometimes seen as bad company and selfish.

The CQC has adopted a value-based approach to human rights (see Chapter 7). It gave three reasons for doing so: firstly, the lack of awareness of human rights amongst inspectors and people in care services; secondly, negative connotations of human rights in care services but less so of values such as dignity; and thirdly, the advantages of using values to specify human rights for inspection purposes (CQC, 2014a). This study did not aim to test the CQC's hypotheses. However, the findings do suggest that associations between human rights and values may provide a constructive basis from which to explore participants' perspectives on the potential role of human rights in care homes and potential problems. Indeed, some care ethicists have criticised human rights for being so abstract that they cannot help to identify specific topics and problems concerning individuals and groups in society, and for not adequately considering the concrete realities of human beings, their relationships and their experiences (Nedelsky, 2008 p. 151; Herring, 2014 p. 4). Concepts such as dignity have also often been described as elusive and hard to define in practice. In this study, these concepts triggered a purpose-led identification and definitional processes that could help to pin down the potential role of human rights in care homes and what that means in practice. In some instances, associating human rights with values helped participants to translate the concept of human rights into their own contexts and make them actionable. This became more apparent when exploring the concept of privacy with the participants, as discussed in more detail later in this chapter.

There is a broad body of academic literature on values and what they mean for people living in, working in and visiting care homes. However, this literature rarely makes a direct connection between such values and human rights. Having said that, more studies have been linking the

concept of dignity in care homes with human rights (e.g. Meenan, 2016; Cahill, 2017) and this thesis contributes to that literature.

10.3 Perspectives on the potential role of human rights in care homes

The discussion about definitions and associations provided the starting point from which to deduce the perspectives on the potential role of human rights in care homes. Here, this thesis contributes to a broader understanding of human rights in care homes for older people. It does so by highlighting the personal context, psychological and relationship aspects that may influence how individuals in care homes approach and understand the topic.

The following sections discuss each perspective in the light of the findings of Chapters 7 to 9. Within the broader approaches and perspectives, the participants provided even more concrete perspectives. These are presented in the text and summarised in Figure 10.4. Similar to the perspectives from the academic literature, many of the participants' perspectives envisage human rights as playing an instrumental role in achieving certain outcomes. From other perspectives, protecting residents' human rights is an end in itself.

10.3.1 The social, political and adult social care policy perspectives

The following two perspectives – anti-institutional and rights-enabling – take a broad political, policy and social approach to the potential role of human rights in care homes. They focus on wider questions about older people's treatment and place in society and (mainly) the government's responsibilities to them under human rights law.

The anti-institutional perspective

The anti-institutional perspective approaches care homes as institutions. The starting point is the potentially negative effects of care homes on residents' human rights.

The findings chapters 7-9 suggested that some participants, especially care home managers and relatives, hold this perspective. They made many negative associations between care homes and human rights (see Section 11.1); in particular, care homes as places in which human rights are violated. To some of these participants (mainly relatives), care homes were the last resort when no alternatives could have provided adequate care for their older family members. Here, human rights could play an instrumental role by highlighting the need to develop and fund community-based or other care settings that are not care homes. This role has also been suggested by some academic contributors (Townsend, 2006).

However, from the point of view of the participants in this study, human rights have two more potential roles. One care home manager suggested that care homes *per se* are not inherently undesirable options in older age. Rather, the negative effects of "institutionalisation" stem from two points. The first relates to changes in family social structures under the phenomenon of demographic ageing (see Chapter 1), which result in younger people "dumping" their older relatives in care homes without engaging further with them. This exacerbates the potentially negative effects of care homes: in practice, a lack of family engagement and lack of staff may mean that not enough support is available for older residents with physical and cognitive impairments to be able to leave the building or be entertained. The participant suggested that human rights has a potential role in making family members aware of the negative effects of their perceived lack of engagement and encouraging them to offset these by becoming more involved in the care home community.

The second point relates to residents' choice and control over their stay in a care home. Forcing a person to live in a care home against their will could be framed as a violation of their human rights. The participant's suggestion was to re-envision adult social care provision in England and make all care homes free of charge, assuming that more older people would then choose to move into a care home sooner. The participant argued that this could offset some of the potentially negative effects of institutionalisation. This solution would need to be critically discussed and consider the characteristics of the care home market in England, including funding (see Chapters 1 and 3). Nevertheless, it raises questions about how choice and control over the place where people receive care can affect residents' experiences of living in a care home. The possibility of framing this lack of choice and control as a violation of human rights points to local authorities' responsibilities under the Care Act 2014 to ensure people's well-being and to the government's general human rights responsibilities towards all older people, whether they receive government funding or not.

Thus, the second point from this perspective is to acknowledge potential human rights related challenges and violations in the context of care homes, to analyse the root causes and, by doing so, to open up discussion about rights-oriented solutions to offset institutionalisation. This could consider the government's legal responsibilities under human rights law in addition to wider social considerations and multiple responsibilities for human rights. Of course, legal interpretation and opinion would be necessary.

The potential stumbling blocks and success factors that emerged from the literature were mentioned in Chapter 6. These included the current political and policy climate in which care homes for older people operate. At the time of writing (November 2019), a government Green Paper on the future of adult social care in England (Jarrett, 2019) has been overdue for over one year. With

current political priorities seemingly elsewhere, particularly the Brexit negotiations, the future policy direction remains largely unchartered.

The rights-enabling perspective

The rights-enabling perspective emerged from an interview with two relatives. Similar to the anti-institutional perspective, it approaches the topic from a social point of view by considering the role of care homes in society. In contrast to the anti-institutional perspective, however, it is based on stronger positive associations with care homes in general and between care homes and human rights.

The participants who held the rights-enabling perspective explained that care homes have the potential to enable older people, especially those with cognitive and physical impairments, to continue living as normal a life as possible. This is something that might not be possible if older people stay in their own homes. The participants acknowledged that residents may have social care needs that could not be met in their homes without round-the-clock assistance and certain amenities. In this situation, older people's rights may no longer be respected or protected in their homes. In care homes, on the other hand, the availability of the necessary amenities, care staff on site 24 hours a day and a community of people could "normalise" older people's physical and cognitive impairments and enable them to live a life in which their rights are continuously respected and protected. A body of care home literature provides evidence that care home environments can offer some older people, especially those with physical and cognitive impairments, a better life than they would have in their previous homes (Bally and Jung, 2015; Minney and Ranzij, 2015). This is especially the case if certain pre-conditions are met, which are discussed in more detail in sections on the equal rights perspective and the care-practice-shaping normative perspective. The current perspective focuses on considering care homes as rights-enabling rather than rights-violating:

In England, care homes suffer from a negative image. Public policy has favoured community-based alternatives within a system of progressive marketisation of care homes, and fewer care home places are now funded by the public purse. From this perspective, there is the potential to highlight the government's responsibility for ensuring that all older people's human rights are protected and that care homes have a place in society to make ageing with rights a reality. At the heart of the UNCRPD (see Chapter 2) are the human rights model of disability and the principle of normalisation. Under the UNCRPD, the government has a legal responsibility to ensure that people with disabilities – including many older people in care homes – can live a life that is free from discrimination, with the same level of human rights protection as afforded to people without disabilities. In this context,

care homes could be re-envisioned as positive settings that support a human rights model of disability.

Of course, this requires the conditions inside care homes to be rights-respecting. The government needs to ascertain those conditions, and this is a role that the CQC is arguably executing already. However, the nature of the CQC's regulatory mechanism (see Chapters 3 and 7) favours a rights-violating rather than a rights-enabling approach. Thus, there are questions about whether a rights-enabling perspective on the potential role of human rights could thrive in the current regulatory system.

10.3.2 Law-oriented perspectives

Law-oriented perspectives differ from social, political and adult social care policy perspectives in two respects. Firstly, they focus on human rights and its potential role *within* care homes rather than approaching the topic from a wider social, political and policy point of view. Secondly, they consider human rights mainly as a potential instrument for legal recourse. The first perspective discussed below ("no role": alternative legal avenue) emerged from the interviews, particularly one interview with a resident. The second perspective (legalistic-reactive) was introduced in Chapter 6.

10.3.2.a The "no role": alternative legal avenue perspective

Under the "no role" perspective, human rights are not considered to be relevant to care homes or the people living in them. The participant who held this perspective felt that there were enough laws and avenues for legal recourse available to him without the HRA if his treatment inside the care home did not meet the required standards. Human rights law here is superfluous to other laws, such as those on consumer protection.

The ambivalence about care homes' legal responsibility under the HRA is described in Chapter 4. The underlying cause may be the traditional role of governments – rather than private companies or individuals – as the main duty-bearers of human rights. Furthermore, all care homes have at least a grade 3 responsibility under English laws and regulations, which in turn must be compatible with the ECHR under the HRA. The "no role" perspective highlights the question posed by some academic contributors and legal commentators (e.g. Dow, 2008) about the value in and need for extending direct legal responsibilities under the HRA to all care home providers, given that other laws and regulations enforce human rights indirectly. These may be more suitable than the HRA for achieving redress for certain problems.

When discussing the potential absence of a role for human rights law in care homes, it may be important to specify human rights issues in care home contexts. The one participant who took this

perspective used the example of wishing to get out of bed earlier in the morning. He explained that despite his desire to get up earlier, no staff were available at the time in the morning, which frustrated him and made him feel depressed. However, he also said that this could not be considered as a human rights matter. Thus, there is a question about which issues are relevant to human rights. This is a problem that the CQC encounters when operationalising its human rights approach to regulating (see Chapter 7).

It is outside the remits of this thesis to discuss these questions in any detail. However, this perspective raises some important points. These could be picked up in further research, perhaps involving legal analysis and socio-legal research into how, when and why individuals access the justice system. As mentioned in Chapter 2, the future of the HRA is insecure; therefore, at some point in the future there may indeed be no role for the HRA in the context of English care homes.

10.3.2.b The law-oriented reactive perspective

This perspective was discussed extensively in Chapter 6, section 6.3.2, so it is discussed only briefly here. The participants who proposed this perspective mentioned that human rights law may have a role if something goes wrong in a care home; for example, if residents are abused or mistreated. The main difference between this perspective and the "no role" perspective is the approach to human rights law. One participant rejected the idea of human rights law being relevant in care homes, whilst the others recognised that it could provide legal redress in certain situations. The discussion under the "no role" perspective is relevant to this perspective as well, especially the issues around specifying human rights.

The participants who held the legalistic-reactive perspective also mentioned something that was highlighted by the academic contributors (see Chapters 4 and 6): the potentially necessary pre-conditions that would make it possible to bring a legal claim in the justice system based on human rights law. One participant spoke about the need for access to human rights information, advocacy services, social workers and lawyers who could support people to take perceived human rights violations in care homes forward into the justice system. This poses questions around access to justice mechanisms for care home residents, an issue that is still underexplored in the academic literature.

Few avenues are available for making claims under human rights law and regulation other than the courts (see Chapter 4). The CQC does not investigate allegations of human rights violations. The policy paper *Quality Matters* (Department of Health and Social Care, 2017a) set out potential advantages of care homes providing residents and their relatives with complaints procedures and avenues for redress. In addition, the Local Government and Social Care Ombudsman can receive

complaints from individuals about adult social care providers. Again, there is a gap in the academic research on the possible value of internal complaints procedures in care homes and the Ombudsman with regard to older residents' human rights. However, given some of the stumbling blocks regarding access to justice on the basis of human rights law, further research on the potential role of internal and other complaints mechanisms in protecting residents' human rights would be valuable.

10.3.3 The normative context shaping perspectives

The normative context shaping perspectives approach human rights not primarily from a legal point of view, but from a normative, care home context shaping angle. They are concerned with the characteristics and practice of care and service provision as an essential part of respecting and protecting residents' human rights. These perspectives recognise older people as equal rightsholders and tackle questions about what this means for how care and services are provided. The equal rights, issue-based and care practice perspectives are discussed below.

10.3.3.a The equal rights and issue-based perspectives

The equal rights perspective focuses on care home residents as entitled holders of human rights. The academic contributors to this perspective paved the way to care home residents being acknowledged as equal rightsholders under the international human rights framework (see Chapter 6). The issue-based perspective focuses on the topics that are considered salient in care homes for older people (see Chapter 6). It became apparent in the interviews that these perspectives overlap in many ways; therefore, they are discussed together in this section.

The CQC experts mentioned some points for discussion under these perspectives. They considered that human rights can be an instrument to identify and tackle ageist assumptions and practices in care homes. They identified issues around sexuality in older age and gender identity as examples, and proposed that viewing these through a human rights lens could encourage people in care homes to challenge their perceptions and ageist assumptions. One of the main purposes of the debate on human rights and older people is to respond to and tackle ageism (see Chapter 2). The equal rights and issue-based perspectives both take on that role in the context of care homes.

From a practical point of view, two CQC inspectors explained that during inspections they adopted an equal rights argument with care home managers and staff to highlight the importance of human rights issues they have identified. Indeed, a study from Germany on care workers' awareness and knowledge of human rights showed that decision-making based on human rights can help care workers to resolve ethical dilemmas and communicate them to residents' relatives (Emmer DA Green et al., 2017). On the other hand, one participant in the present study expressed her

frustration with care workers who used an equal rights argument to explain why they did not respond to the care needs of her mother, who had advanced dementia. The difficulty of balancing respect for older residents' equal rights with duties of care were prominent in the findings of this research, especially in the context of residents with severe cognitive impairments. This aligned with the academic research analysed in Chapter 6 and is discussed further under the "no role" safety-focused perspective.

One other participant mentioned residents' rights to participate in social and cultural life. She suggested that under human rights law it is the government's responsibility to protect this right; for example, by making funds available for buses to take residents to social and cultural events. This participant raised a potentially important topic. From the equal rights perspective, all residents have the same rights as others in society, including the right to education and the right to vote (see e.g. Scourfield, 2007; Riekkinen, 2015). Under the current legal and regulatory framework for human rights governing English care homes, there are questions about who is ultimately responsible for respecting, protecting and implementing these rights. The trickling-down process of transferring human rights responsibilities to non-state actors was described in Chapter 2. In Chapter 4, it was argued that this process has only taken place to a limited extent in England with regard to care home providers. An equal rights perspective, therefore, could open up discussion on the potential role of the government and local authorities (as the traditional main duty-bearers) to ensure that *all* human rights of older care home residents are adequately protected.

10.3.3.b Care-practice-shaping perspective

The care-practice-shaping perspective was shared by many participants, including the CQC experts and care workers. Here, the focus is on how human rights could shape care practice inside care homes. There are two approaches from this perspective. The first considers the provision of social care in the context of residents' rights. The second looks at the ethos of organisations, with human rights as a guiding value. This is comparable to the CQC's human rights approach (see Chapter 7). These two approaches are discussed in turn.

1. The potential importance of person-centred care for human rights in care homes

The academic contributors who hold this perspective framed person-centred care as a human rights approach that puts the individual and their needs at the centre of care planning (see Chapter 6). In the international debate on older people's rights, person-centred care is widely accepted as good practice (see Chapter 2). The findings of this study confirmed that the CQC experts and many of the care home participants (especially the care workers and care home managers) made associations between person-centred care and human rights. Their associations included many underlying

principles of person-centred care, such as individuality, autonomy and respect. A CQC expert explained that a person-centred approach to providing social care can help to "increase" human rights; thus, it can help to respect human rights in care homes. In addition, person-centred care is one of the minimum standards that care homes have to meet under the CQC's regulatory framework (see Chapter 3). The regulation does not explicitly refer to human rights as a concept. However, person-centred care could be elevated to a recognised matter of international and national human rights law, whereby people are entitled to receive person-centred care from not only their care home but also the government as the main duty-bearer of human rights.

Many of the care workers were familiar with the steps involved in providing person-centred care, and they made associations between it and human rights. According to some care workers and care home managers, good practice under a person-centred approach included involving residents in making decisions about their own care and listening to their needs and concerns. However, these participants also explained that when they encounter ethical dilemmas in providing everyday care, they find ways to address the complexities in the principles of person-centred care or find other avenues of orientation. This was especially the case when they felt that residents' decisions were "unwise", unsafe or could put the rights and well-being of other residents or staff at risk. Techniques in such situations included using legal instruments such as DoLS, and communication strategies to persuade residents to change their views whilst accommodating their wishes in creative ways. Under the MCA 2005, care workers must support people's decision-making, even if the decision seems unwise, and find the least restrictive options before applying for DoLS. However, the findings of this study are largely in line with the findings of the Everyday Decisions Project on supported decision-making (Harding and Tascioglu, 2017), which was briefly introduced in Section 2.3.2. The authors highlighted that care professionals supported disabled people with making everyday decisions and life choices. However, when the decisions were more complex, care professionals often "defaulted to substitute decisions made in the person's best interest" even though providing more support could have been more appropriate. These decisions related to areas such as finances, health, intimate relationships and friendships (Harding and Tascioglu, 2017 p. 20). The findings of the present study suggest that some care professionals encounter difficulties when trying to balance rights under the MCA with risk assessment and duty of care.

Many care workers also referred to the "Mum test", by which a perceived dilemma is resolved not through a person-centred approach but by asking oneself, "How would I want to be treated in this situation?" or "How would I like my mum to be treated?" This implied that the principles of person-centred care can provide only limited guidance and solutions in circumstances of ethical or even

MCA-related legal dilemmas. The participants in this study did not mention the steps involved in best-interest decision-making (as set out in the MCA) or how these could complement the principles of person-centred care in practice.

The nature of the relationships between care workers and some residents and family members further complicated the continuous provision of person-centred care. Some care workers described how they feared receiving critical feedback from relatives of residents who did not approve of the choices made by their older family members. One relative said that a care worker's reference to her older mother's rights in order to justify a perceived lack of physical hygiene invoked anger and other negative emotions. To manage such relationships, some care workers explained that they documented residents' choices so they could share them with family members. In some cases, this included information about residents' sexual activities and other private matters, which could amount to a violation of residents' privacy rights. This confirmed findings reported by Backhouse and colleagues (2018) on potentially harmful practices to tackle "challenging" behaviour (see Chapter 6).

Whilst the concept of person-centred care is now recognised as a human rights approach, the interviews revealed that there are complications in practice. This supports some of the academic contributions mentioned in Chapter 6. If person-centred care is central to considering the human rights of older people living in care homes, further discussions must focus on such dilemmas, taking into consideration the complexity of relationships in care homes and the value of laws, such as the MCA.

The residents themselves often mentioned that they wanted more compassionate and friendly sociable time and communication with care workers, outside the support provided with ADLs. This raises a question about what precisely is entailed in person-centred care as a human rights approach, and whether it includes a legally enforceable right to compassionate care and caring relationships. This is especially pertinent if person-centred care is increasingly considered a matter for human rights law. Some contributions to the ethics of care debate (see Chapter 2) could be useful to further define the potential role of human rights in the context of providing person-centred care. Herring (2017), for example, discussed the link between care, the human need for compassion and caring relationships, and the law. He explained how a relational approach to human rights can help to frame environments in which caring and compassionate relationships can flourish, without necessarily making them enforceable in court. In this approach, human rights becomes an instrument to encourage individuals to act in a way that promotes such relationships in contexts of

care (Herring, 2017 p. 164). The MCA, with its relational approach to best-interest decision-making, is an example of this.

2. Human-rights-based care-ethos perspective

This perspective was introduced in Chapter 6. From this perspective, human rights in care homes can underlie an organisational ethos in order to create "care home cultures of human rights". In the findings of this study, this perspective was revealed in the CQC's 2017 milestone document. Here, the CQC suggested that adopting an organisation-wide ethos underpinned by human rights can enhance a care home's service provision and even help it achieve an "outstanding" rating. The CQC itself is integrating human rights into its organisational culture, although it is experiencing challenges along the way (see Chapter 7).

To base its organisational ethos on human rights, a care home needs to recognise as rightsholders not only its residents but also everyone else in the care home system, notably care workers. It must recognise that the relationships between people in the care home environment are important for creating care cultures that are underpinned by human rights. The roles that human rights could play from this perspective were spelled out clearly in the 2017 milestone document and by some of the care home participants interviewed for this study.

Firstly, recognising the rights of staff could influence the quality of care provided for residents. In practice, this could mean that care homes use value-driven recruitment processes to ensure that they recruit only those applicants whose values and mindset match the care home's ethos. It may also mean encouraging members of staff to raise concerns and supporting them to find solutions in situations that present ethical dilemmas. The value of equality can be promoted; for example, by connecting members of staff to support groups outside the care home or supporting them when they experience racist behaviour in the care home.

Secondly, having a culture that is based on human rights may encourage a care home to improve its services in relation to human rights considerations. That may involve finding solutions to issues around securing residents' privacy and their right to participate in social life. Furthermore, human rights risk assessments could be introduced to avoid possible violations. Again, connecting with external expertise to overcome any limitations is part of this perspective.

However, several steps must be taken to truly integrate an ethos into an organisation so that the new organisational culture is sustainable (see Chapter 7). Some of the CQC experts interviewed in this study expressed the opinion that care workers and care home managers lacked awareness and knowledge of human rights and that the HRA suffered from too many negative connotations to have

a central role in care homes. One participant mentioned that care homes may provide "good care" but that people in care homes did not make the connection to human rights. The findings of this study show that almost all the participants had at least had some level of understanding of the core concept of human rights. However, even though participants' definitions of good care aligned with their definitions of human rights in care homes, only a few made a direct link between the two. This may be due to communication, understanding, awareness or other factors. Thus, there are questions about how to overcome these initial stumbling blocks to creating an organisational ethos based on human rights.

The CQC experts mentioned that human rights training could help to raise awareness. However, a recent controlled trial on human rights training for care workers in care homes and hospitals suggests that its value is questionable (Kinderman et al., 2018). The study suggested that targeted training could raise awareness and knowledge of human rights but found no evidence that it changed care practice behaviour in care workers (see Chapter 6). Examining the literature on organisational change in care homes could help to further define what is necessary to integrate human rights into care home cultures and what this entails in practice.

The CQC has adopted a value-based definition of human rights for its regulatory purposes, rather than a definition that spells out the rights and freedoms contained in international human rights instruments. For various reasons given in this thesis, the CQC prefers values over rights and freedoms. This raises the question of whether an organisational culture that is based on human rights must in fact be based on human rights law or whether it can also include a value-based ethos. As argued in Section 11.1, a value-based ethos may help people in care homes to define what a particular value means to them. Ultimately, the answer to this question depends on the purpose of a potential human-rights-based organisational culture and the application of human rights in care homes in general.

Care homes can be viewed as communities of people, with relationships unfolding between residents, staff and relatives in complex contexts (see Chapter 3). The relationship-centred care approach (see Chapter 3) focuses on the inter-relatedness and interdependence of different groups of people in care homes. Whilst this perspective recognises that residents' and staff's rights are intertwined, the human rights of family members and relatives and their potential role in care homes were not mentioned from any of the perspectives.

10.3.3.c The "no role" safety-focused perspective

Some participants did not think that human rights had a normative role in shaping the care home for residents or care workers. Their perspective is termed the "no role" safety-focused perspective.

Participants who held this perspective usually gave a definition of human rights. In their opinion, people with severe cognitive impairments were not rightsholders. Explicitly or implicitly, they also associated human rights with freedom and autonomy, which they felt that people with cognitive impairments could no longer profit from due to capacity and safety considerations. Care homes, from this perspective, are places that care for people who do not have the capacity to care for themselves. Therefore, residents' safety should be paramount for care home staff. As such, "stripping" care home residents of their human rights was considered necessary for their own safety; and safety concerns justified what one relative referred to as "humanitarian incarceration". The MCA 2005 protects people's right to autonomy and decision-making and puts in place processes for doing so in care homes (see Chapter 2). People with impairments that may limit their decision-making capacity are still equal rightsholders under the UNCRPD. The participants (mostly relatives) who held a "no role" safety-focused perspective did not discuss these legal frameworks, which may indicate a lack of awareness. This again reflects some of the findings in the literature, which identified a lack of awareness and understanding of the UNCRPD in the care sector (Harding and Tascioglu, 2017 p. 6).

As reported in the findings chapters, balancing residents' rights with the need to reduce risk and ensure safety presented a dilemma for many participants. Some argued that human rights considerations complicated relationships between care workers and residents and between care home staff. This may even imply a potentially "negative" role for human rights in care homes. Here, the concept stands in the way of "good, safety focused" care and may be counter-productive to residents' health and well-being, which could be framed as a human rights issue in itself.

This perspective makes clear the importance of defining human rights (and their possible limitations in the face of impairment-related risks), the purpose of "caring" in care homes, and its relationship to human rights, the responsibilities of care home staff, and human rights in practice. This is especially relevant to care home residents with severe cognitive impairments. Further research is needed into awareness and practical application of the UNCRPD and the MCA, and how they relate to the ECHR and human rights as a normative framework.

10.3.4 The whole-system perspective

The whole-system perspective takes into consideration most of the perspectives discussed above (see Chapter 6). Some of the CQC experts and the 2017 milestone document adopted such a perspective. The "system" here is comprised of care homes, regulators, commissioners and policy makers, all of which share the purpose of "putting equality and human rights at the heart of quality improvement" (CQC, 2018b).

The potential role for human rights in this perspective that emerged from the findings are as follows:

1. To recognise all people in care homes as equal holders of human rights and thus to challenge discriminatory practices. This is in line with the human-rights-based care ethos perspective.

2. To recognise human rights as both a legal and a normative instrument. The CQC views human rights law as an instrument with multiple purposes. One such purpose is to hold care home managers and care workers accountable through regulatory mechanisms for protecting human rights and through the powers of the CQC and the Equality and Human Rights Commission. However, this accountability under CQC regulation is still limited (see Chapter 7). Another purpose is to influence care practice. Here, human rights in law (or rather CQC regulation through the FREDA principles in the KLOEs – see Chapter 7) can be used to develop an understanding of what human rights mean for practice. The CQC's inspection reports and other published information on care quality, including in the 2017 milestone document, build on human rights in law whilst creating a basis for such practice-based information. Using CQC inspection reports to explore the right to privacy is one example of how human rights regulation can support a practice-based understanding.

The CQC also views human rights as a normative tool that can shape care practice inside care homes and in doing so help services to provide better care. Essentially, the 2017 milestone document proposes – but does not demand – that care homes adopt a human rights organisational ethos as far as this is possible. This proposed ethos is not based on legal responsibilities, but on a commitment to enhance service provision.

3. To recognise a multi-level duty for human rights. The CQC stated that protecting human rights in care homes for older people is a matter primarily for the government and local authorities, although it is also of importance for the regulator and people managing and working in care homes. The potential role of human rights here is to raise awareness amongst stakeholders on several levels that a whole-system approach is necessary to protect the rights of care home residents. As a potential barrier to this, the CQC experts mentioned a widespread negative perception and lack of awareness of human rights in care homes. This present study suggests that there are indeed negative connotations of human rights in connection with care homes for older people. Whilst increasing awareness and knowledge of human rights does not necessarily influence care practice, this study suggests that a value-based discussion has the potential to offset negative associations and pave the way for creative discussion around perspectives on human rights.

10.4 SUMMARY

The introduction to this chapter set the scene for exploring the typology of perspectives in the light of the findings of this study. The findings suggest that the "noise" in English society around human rights in relation to older people being abused and neglected in care homes influenced the associations that many participants make around human rights. In turn, this may influence how they relate human rights to their own contexts and perceived realities. This triggered emotional reactions, including negative ones. Value-based approaches to human rights, however, gave some individuals a purposeful and creative ground for exploring the practical meaning of the concept and potential challenges and limitations.

This study has shown that the topic of human rights in care homes can be approached from several angles. Figure 10.4 illustrates the specific potential roles of human rights under the nine sub-perspectives offered by the participants.

Figure 10.4: The potential role for human rights in the context of care homes for older people is…

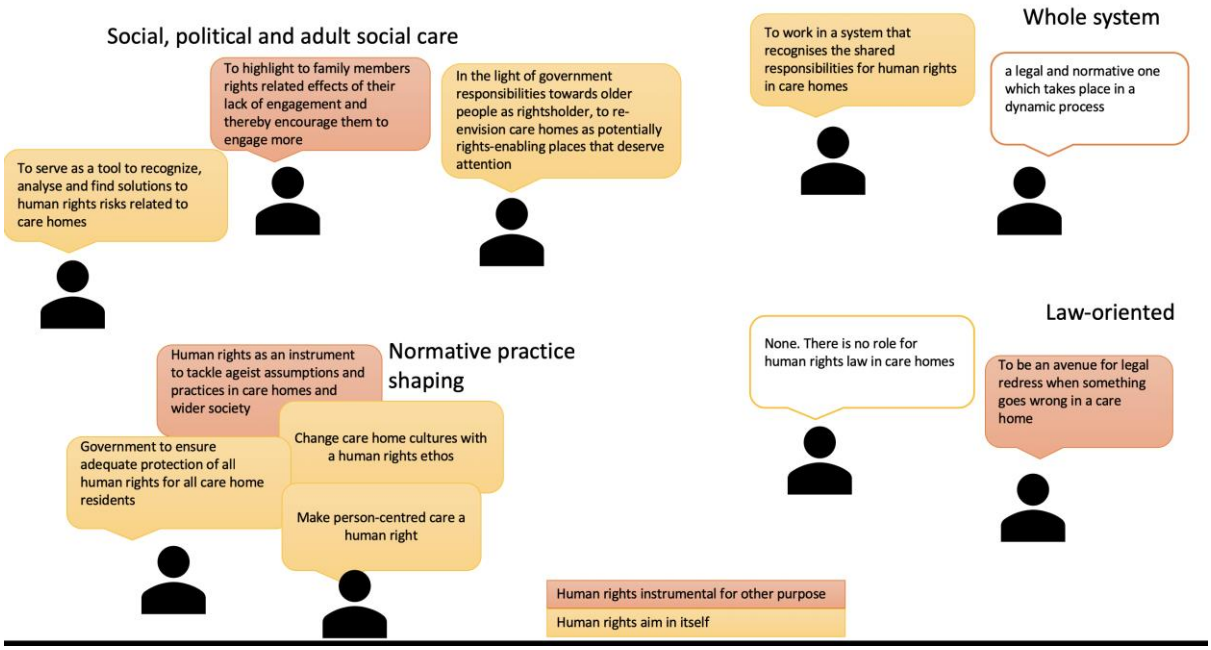


Figure 10.4 The potential role for human rights in the context of care homes is...

11 Perspectives on the right to privacy

One of the objectives of this study was to explore the practical implications of the human right to privacy in care homes from multiple perspectives. As explained in Chapter 1, the right to privacy is legally enshrined in multiple international human rights documents and in Article 8 of the HRA. It encompasses a person's private and family life, their home and their correspondence. Protecting residents' privacy is a fundamental standard for care home providers (Regulation 10, Dignity and Respect). In addition, care home providers are bound by privacy legislation, notably the Data Protection Act 2018. Privacy features widely in international and national debates on the human rights of older people in care homes. Yet, good privacy practice can be hard to define in many contexts (Tugendhat, 2017), including care homes (Bayer et al., 2005). This is especially the case for privacy matters outside the remits of data protection, for which some actionable rules and standards exist.

This chapter focuses on the research findings under research element 3 of this thesis. A review of the academic literature on the evidence for good practice with regard to respecting care home residents' right to privacy was produced as part of the framework for this study. Section 11.1 summarises this review and briefly discusses privacy in the literature on human rights and care homes. Section 11.2 briefly explains the role of the right to privacy in the human rights framework governing English care homes. The subsequent sections report the findings from analysing the CQC documents and the interviews with study participants. To clarify, this thesis does not provide a legal interpretation of the right to privacy as contained in the HRA in the context of care homes. Rather, it proposes a possible normative, practice-oriented interpretation. The findings are then discussed in relation to the typology of perspectives presented in Chapter 10.

The structure of this chapter is different from that of the other findings chapters (7–9). It follows the same first step of outlining associations between the right to privacy and care homes. However, the rest of the structure reflects that the interviews and CQC reports were analysed twice. First, an inductive analysis was used to identify the common themes regarding the definition and conceptualisation of "privacy" across the data. Next, the themes were used as a coding framework to draw out perspectives on positive and negative privacy practices.

This analytical strategy revealed a possible purpose for the right to privacy in care homes. In addition, six topics on privacy in care homes and three key factors for maintaining residents' privacy emerged. A right to privacy in care homes model was developed on the basis of these findings. Furthermore, a list of exemplary and poor practice points was created from the perspective of the

CQC and the participant groups. Some common views on challenges to maintaining privacy in care homes were also listed. These findings are reported in sections 11.4 and 11.5. The findings are discussed in Chapter 12, taking into consideration the typology of perspectives.

11.1 Theorising privacy

Privacy has been identified as essential for values such as autonomy, individuality and freedom (Westin, 1967; Miller, 1971; Bloustein, 1984). The topic of data privacy has attracted public and academic debate due to the introduction of the Data Protection Act 2018 and the challenges that stem from the internet, artificial intelligence and other technologies (see Chapter 2).

Despite the importance attributed to privacy as a concept and the existence of the human right to privacy, the concept (see Chapter 1) has long been considered an elusive one, and its exact meaning is in "disarray" (Solove, 2008 p. 1). The right to privacy as contained in the ECHR has been used in court. It, too, has been argued to "defy precise definition" (Tugendhat, 2017 p. 132). Nevertheless, academic thinkers have developed theories with the aim of making the concept more understandable in practice. An article published in 1890 defined the right to privacy as "the right to be let alone" in response to technological and journalistic advancements (Warren and Brandeis, 1890 p. 195). Their main concern was around privacy and the media. They established that the right to be let alone equates to a "general immunity of the person, the right to one's personality" (Warren and Brandeis, 1890 p. 207). Posner, on the other hand, understood privacy as not only the right to be left alone, but also the right to secrecy and concealment of certain information (Posner, 1977). Other conceptions of privacy focused on the idea of personhood and protecting certain aspects of an individual's personality. Reiman, for example, defined the right to privacy as the protection of a person's interest in "becoming, being and remaining" (Reiman, 1976).

However, Solove (2008) argued that all these theories on privacy fail to adequately define it for the purposes of law and policy making. He wrote: "Although… conceptions of privacy… elaborate upon certain dimensions of privacy and contain many insights, setting upon any one of the conceptions results in either a reductive or an overly broad account of privacy" (Solove, 2008 p. 37). He proposed an alternative theory that consists of four principal dimensions: a method; a degree of generality; a structure that accommodates variability; and a focus (Solove, 2008 p. 41). According to Solove, privacy cannot in itself provide adequate guidance for law and policy on all relevant topics in society. Rather, privacy should be conceptualised according to specific legal and policy contexts. These may include the home, the family and the body, amongst others.

The first dimension of "method" is to consider privacy as "not one thing, but a cluster of many yet related things" (Solove, 2008 p. 40). "Generality" refers to an approach to privacy that is contextual yet generalisable. Solove explained this as follows: "A theory of privacy must establish a balance between generality and particularity. Although my theory of privacy is contextual, it also generalizes to provide a framework for understanding a broad range of privacy problems" (Solove, 2008 p. 41). Under the third dimension, "variability", any theory of privacy must allow enough flexibility for "multiple attitudes and beliefs about privacy" (Solove, 2008 p .41). Here, Solove recognised privacy as a matter of pluralism and social constructionism, with several perspectives on one contextual topic. Under the fourth dimension, "focus", Solove argued that all conceptions of privacy should focus on a specific problem or topic.

Although Solove's theory of privacy did not guide the data collection and analysis process of this study's component on the right to privacy, Chapter 12 will refer back to Solove when analysing the results of this study. Indeed, some authors have attempted to conceptualise and define the right to privacy in order to capture its normative meaning for care practice in hospitals (Woogara, 2005) and in care home settings (Emmer DA Green et al., 2018). The review of the literature on privacy in care homes for this study notes that many academic contributors understand the purpose of the right to privacy as furthering a certain overall aim, such as protecting residents' control, choice or dignity (Emmer DA Green et al., 2018 p. 205).

When translated into practice, the concept is often considered to be multi-dimensional, covering physical, inter-relational, social and psychological aspects. The physical dimension relates mostly to the availability of private (as opposed to communal) spaces in care homes: primarily private bedrooms and single-use lavatories and bathrooms, often referred to as 'en-suite'. The psychological dimension often refers to residents' control over privacy-related matters, including their bedrooms, their sexuality and their sexual activities (Emmer DA Green et al., 2018 p. 205). A further dimension mentioned in some of the academic literature relates to data privacy and protecting residents' personal data (Pau Le Low et al., 2007; Hall et al., 2014; Fisk, 2015). In many areas, the dimensions overlap when it comes to reported good privacy practice in care homes. The contributors here have mostly discussed good practice regarding care home residents' private bedrooms. Residents should be able to maintain as much choice and control as possible over the décor of, use of and activities in their private bedrooms. It is considered good practice to allow residents to choose freely between staying in their bedrooms or leaving them to spend time in communal areas. Care home staff and other residents should respect this private space; for example, by knocking on doors and entering only with permission. Locks or privacy notices to hang on doors should also be made available.

Authors have discussed some of the contextual challenges that care home staff face when trying to balance the right to privacy with caring for people who have severe dementia or other cognitive impairments. In dilemmas that concern residents' sexuality, questions around the capacity to consent to sexual activities take priority over privacy considerations (Knaplund, 2009; Hillman, 2016). However, none of the contributions reviewed on the right to privacy in care homes attempted to draw on Solove's theory of privacy to develop a full account of the concept, and the meaning of the right to privacy, in care home settings.

The findings of this study add to the multi-dimensional conceptualisation of the right to privacy in care homes for older people. The findings suggest that the core context in which the right to privacy is to be conceptualised in the care home is privacy in the "home". The dimensions are referred to as "privacy topics" and "key aspects". This thesis argues that in care come contexts the main purpose of the right to privacy is to set boundaries between people in the care home community that protect a resident's "home" inside the care home.

11.2 The right to privacy in the human rights framework governing English care homes

The human rights framework governing English care homes was introduced in Chapter 4. In this section, the right to privacy in this framework is considered. It focuses briefly on the legal aspect before providing a more focused outline of the regulatory aspect.

11.2.1 The right to privacy in the legal framework

The right to privacy features in Article 8 of the ECHR and the HRA. In theory, care home residents who are funded by their local authority could take their care home provider to court over a privacy matter (e.g. Cooper, 2002). Furthermore, people in care homes who control personal data must keep to the Data Protection Act 2018.

11.2.2 The right to privacy in CQC regulation

The concept of privacy is central in CQC regulation and inspection mechanisms. This is evident in the CQC's human rights milestone documents, which authors argued that the "right to a private and family life" underlies most of the problems in health and social care settings (CQC, 2014a p. 9; CQC, 2019g p. 14).

Privacy features explicitly in the CQC's fundamental standards (Regulation 10) and in the KLOEs. For example, Regulation 10(2)(a) (Dignity and Respect) states that "each person's privacy must be maintained at all times". One of the KLOEs asks the question: "How does a service respect and promote people's privacy, dignity and independence?" (KLOE C3). In this way, the KLOEs help to define the fundamental standard of "maintaining" privacy. Service providers must do more than

respect privacy in a passive way; they must actively take steps to promote a sense of privacy in a care home environment.

The fundamental standards and KLOEs refer to privacy as a concept. However, the CQC's human rights milestone documents, notably the one from 2014, emphasise the centrality of the "human right to a private and family life" (Art 8 ECHR) rather than privacy for the CQC's purpose of regulating and inspecting services (CQC, 2014a p. 30; CQC 2019g pp. 14, 34). According to the CQC, in care contexts the right to a private and family life is the most relevant of all human rights contained in the HRA (see Chapter 7, section 7.3) . This is because most problems found when inspecting care services are related to the right to a private and family life (CQC, 2014 p. 9). The organisation states:

> A large number of human rights issues in health and social care fall into Art 8 – the right to private and family life… Some human rights issues are relevant to more than one Article. For example, neglect… may be a breach of Art 8 or Art 3 (freedom from inhumane and degrading treatment). (CQC, 2014 p. 9)

The same document argues that integrating the FREDA principles into regulation and inspection mechanisms will help inspectors and providers to understand the right to privacy and put it into practice. This is because three of the FREDA principles – respect, dignity and autonomy (choice, control) – directly relate to the right to a private and family life (CQC, 2014a p. 30; CQC, 2019g p. 34). The organisation explained:

> [Art 8] is not a very easily understood article. It is broadly defined by law. Therefore it is difficult for inspectors, providers and people who use services to easily grasp the scope and issues contained in Art 8. We are trying to build an approach that is easily understood by people who are not human rights specialists. (CQC, 2014a p. 9; CQC, 2019g p. 14)

However, none of the documents (relevant regulations, KLOEs or human rights milestones) provide clear guidance for care home managers and their staff on privacy practice in care homes. Rather, the relevant sections in these documents are broad and conceptual rather than defined and actionable. The following statement from Regulation 10 highlights this:

> Each person's privacy must be maintained at all times including when they are asleep, unconscious or lack capacity… (Regulation 10(2)(a))

There are some exceptions. Regulation 10, for example, also mentions that residents should not have to share sleeping accommodation with someone of the opposite sex and that they should have access to segregated bathrooms without having to pass through areas that are designated for the opposite sex (Regulation 10(2)(a)).

In addition, there is some specialised guidance on privacy, such as the CQC's statement on the use of surveillance equipment in care homes. This contains the following:

> If you use surveillance, you must do this in a way that treats people with dignity and respect… People who use your service or their families may raise concerns about privacy. If they do, you must take steps to address them. Aim to make the impact on people's privacy as small as possible. (CQC 2018c)

This document also provides practical guidance. It advises care home staff to ensure that surveillance material can only be accessed by authorised people and to switch off any cameras when providing personal care (CQC, 2018c). Providers must act in accordance with legal requirements to use surveillance cameras lawfully in care homes.

11.2.3 The right to privacy in CQC inspection reports

The quantitative content analysis method was used to analyse care home inspection reports. This revealed the importance ascribed to privacy by CQC inspectors when inspecting care homes, at least in the reports collected for this study. Of the 104 inspection reports that were analysed, most contained at least one mention of how privacy is maintained or breached in a particular care home. Around thirty reports did not mention privacy. However, most of those reports referred to one or more of the related FREDA principles: dignity, respect and independence. The concept of independence was interpreted widely to include autonomy, defined as "choice and/or control". As such, 95% (n=104) of all inspectors mentioned privacy, the right to privacy or related concepts. However, none of the reports mentioned the human right to a private and family life. This is perhaps in line with the CQC's FREDA-based definition of human rights and the wording in the relevant regulation (Regulation 10). Table 11.1 summarises these numbers.

Table 11.1 The right to privacy in the study's sample of CQC inspection reports

Inspection reports and privacy	%
Number of inspection reports (n=104) in % that mention one or more aspects of "maintaining privacy" in a care home	72%
Number of inspection reports (n=104) in % that mention one or more aspects of "maintaining privacy" in a care home OR related concepts of respect, dignity and autonomy	95%
Number of inspection reports (n=104) in % that refer to "the human right to a private and family life"	0%

11.3 The right to privacy in the interviews with people living, working and visiting care homes

The CQC documents and interviews collected for elements 1 and 2 of the study also served element 3. The previous findings chapters described some of the difficulties around discussing the topic of human rights with some research participants. This was hardly the case when speaking about the right to privacy. Most participants said that maintaining residents' privacy was an important consideration in a care home, and they all felt able to comment on what maintaining privacy or having a sense of privacy entailed in that context. There were significant trends and commonalities in the participants' associations with the right to privacy and their thoughts on what respecting and promoting that right meant in a care home.

The following sub-section notes the common associations amongst care home managers, care workers and CQC experts between privacy and the concept of home. Afterwards, the right to privacy in care homes model is introduced. This is followed by a discussion about common practice points mentioned in the CQC reports and by participants.

11.3.1 Privacy and the right to privacy: participant's associations

The participants were invited to share their perspectives on the relevance and meaning of the right to privacy in care homes. A common theme that emerged in the responses from the CQC experts, care home managers and care workers was the association between privacy and the concept of home. Furthermore, there was a common association between the right to privacy and the relationship boundaries between people who live and work in care "homes". Interpreting relevant statements from participants, the concept of privacy and the concept of home can be regarded as two sides of the same coin: privacy means home and home means privacy. The following statements illustrate this:

Privacy is home

> [Privacy is significant because] This is the person's home and this is where they live. (CQC, expert 1)

> Privacy is relevant because the people that live with us, this is their home and not ours. (Participant 103, care home manager)

Home is privacy

> Privacy is all of those little things. It is the foundation of somebody feeling at home. (Participant 104, care home manager)

> That is their home, their space… it's their privacy. (Participant 307, care worker)

The dimensions of privacy in the home were filtered out and translated into six privacy topics, which are presented in Section 10.3.2.

With regard to the concept of home, some participants suggested that care homes cannot replace the experience of residents' "own homes": the places in which they lived before they moved into a care home. Rather, the participants felt that care homes were residents' *new* home. Some participants felt that a new home signifies a different stage in life. For example, family life might have played a central role in residents' previous homes, and this cannot be replaced in a care home. The participants suggested that in this new life situation and in this new home, the care home staff and other residents can become an integral part of a resident's experience of being at home. The following statements illustrate this:

> My way of thinking is that, literally to try to make that person feel – never going to replace home and family. But this is their home, it's not our rules and our restrictions and us doing to you. It's how can we help you to live in a smaller box. (Participant 104, care home manager)

> This is their home and we are just privileged to work in their home. (Participant 308, care worker)

When discussing the right to privacy, some participants associated this with trusting relationships between care home residents and staff, and some associated it with legal rules that staff have to follow to protect a resident's right to privacy in their new home. The following statement is illustrative:

> If you give them their space and protect their [right to] privacy, they are more likely to trust you… If you are not giving them privacy this may lead to embarrassing situations. (Participant 301, care worker)

Protecting the right to privacy, therefore, involves setting boundaries between people living and working in care homes. These boundaries were filtered out of the interviews and translated into three key aspects, which are presented in Section 10.3.2.

However, none of the relatives or residents who were interviewed associated privacy directly with the concept of home. Rather, some residents expressed a wish to return to their previous homes. They defined the concept of a home as their properties (such as houses, flats or bungalows) and/or the lives they led in those properties, including their family life. At least five residents spoke about their properties and their wish not to sell them, to go and visit them or to move back into them permanently. At least two residents longed to return to live with their families. This is illustrated in the statements below:

> It's rather sad… It hits me every so often to think that I don't have my home any more. (Participant 206)

> I want to try and get back into my own home. (Participant 210)

Many of the relatives associated the right to privacy with specific practice points in care homes, and these are described in more detail below. None of the relatives felt that privacy as a concept had an overarching purpose in the lives of their parents or grandparents in a care home. Indeed, some of them did not think that privacy was particularly important to their relatives in the care home. Rather, many relatives felt that their family member did not share the same concept of privacy and the right to privacy as their care workers and managers did. The following statement illustrates this:

> My dad doesn't realise what privacy is because they [care workers] believe it is sort of the opposite, whipping everything up like drawing the curtains whereas my dad tends not to be particularly bothered. (Participant 410)

Other relatives made negative associations between privacy and issues such as social isolation behind closed bedroom doors. They expressed concerns that too much privacy could lead to their family member not integrating enough into communal life, as this relative explained:

> Privacy – I don't think a lot of them [residents] would like that. They would feel isolated. (Participant 405)

> When she [referring to the resident] wants her door closed all the time, it is closed all the time. I always open it because I feel claustrophobic in there and I think it is good for [name of resident] to see people walking up and down rather than sitting in there on her own. (Participant 407)

11.3.2 The right to privacy in care homes model

The findings presented in Section 10.3.1 suggest that there is a difference between the concepts of privacy and the right to privacy. Whilst the concept of privacy can be linked to the concept of home, the potential purpose of the right to privacy is to set normative boundaries for relationships in the care "home". To further define the potential meaning of the concept of privacy in care homes, the interviews and CQC reports were analysed for common themes. These are referred to here as "privacy topics". The analysis also revealed that the right to privacy in care homes is associated with three key aspects for setting boundaries. The six privacy topics and three key aspects are discussed below.

11.3.2.a Defining the concept of privacy in the care "home": the six privacy topics

Each of the following "privacy topics" refers to a set of issues relating to one aspect of care home life that inspectors and all care home participants frequently picked up on when talking about privacy.

1. Residents' physical space in the care home: This topic relates to the care home environment and includes the floor plan, communal spaces and bedroom type (single or multiple use, with or without en-suite bathrooms). The topic also includes equipment and amenities in the care home; for example, hoists, privacy screens, electrical hardware and internet access.

2. Residents' day and night time: This topic relates to residents' daily routines and structures. It includes activities, religious ceremonies, meals and sleeping times.

3. Residents' care: This topic covers residents' social care needs, as attended to in the care home environment.

4. Residents' personal data: This topic concerns residents' personal information and their health and social care data. Importantly, it also includes day-to-day information and notes on events (during the day and night) that are related to a resident. Examples include a resident's choices about their personal care or meals, and their wishes to spend time alone or with someone. This topic also includes information about a resident's sexual orientation.

5. Residents' families and relationships with people outside the care home: This topic is about residents' family life and their relationships with people who do not work in the care home. This

includes visiting times in the care home, opportunities for spending time in private with visitors, and couples living together in the care home.

6. Residents' bodies and physical appearance: This topic includes all matters to do with residents' bodies beyond their basic personal and social care needs. It extends to issues of sexuality and physical appearance, such as nails, hair care and make-up.

These six privacy topics are not mutually exclusive but inter-related. For example, residents' care is directly related to residents' physical space in the care home and to residents' bodies and physical appearance.

Three key factors defining the right to privacy in care homes

The following key factors define the right to privacy in care homes in relation to the six privacy topics.

1. Availability of suitable space and amenities in the care home: The first key aspect considers the physical care home environment and how it relates to each privacy topic. Based on the findings, it recognises the importance of floor and room planning in care homes, the availability of the right equipment, room décor and amenities for respecting the right to privacy. For example, under privacy topic 1 (Residents' physical space in the care home), this key aspect included the availability of single bedrooms with en-suite facilities and the availability of bedrooms for couples. Under privacy topic 3 (Residents' care), this key aspect included matters such as lockable doors and windows with curtains. Under privacy topic 6 (Residents' bodies and physical appearance), this key aspect related to, for example, having the necessary amenities to care for residents' appearance, such as laundry and hairdressing services.

2. Ensuring residents' choice and control: This key aspect concerns the resident and their "right" to have choice and control within each privacy topic. It puts the resident at the heart of the right to privacy and each privacy topic in the care home context. For example, under privacy topic 3 (residents' day and night time), this key aspect related to residents being able to choose when to spend time on their own or with others. Under privacy topic 4 (residents' personal data and information), this key aspect covers residents having a say about how their personal data is handled and shared.

3. Respectful relationships between care workers, managers and residents: The third key aspect helps to define the correlative duties of care workers and others in the care home community to maintain every individual's right to privacy. In general terms, this duty involves respecting the right to privacy; thus, residents' choices and control within the six privacy topics. For instance, for privacy

topic 5 (residents' families and relationships with people outside the care home), this key aspect included care workers respecting residents' time with family and friends. Another prominent example concerned privacy topic 1 (Residents' physical space) and how care workers and others in the community respect a resident's bedroom.

The three key aspects are relevant to all the privacy topics. Together, they form a web of distinct yet inter-related and interdependent dimensions of privacy, and the right to privacy, in the home. If any of these dimensions are disrupted, the whole web – and, thus, a resident's privacy in the care home – is damaged.

Table 11.2 sets out the topics that were commonly raised in the interviews and inspection reports, and how these relate to each privacy topic and the key aspects. Taking these findings into consideration, section 11.4 reports on perceived good and poor privacy practice in care homes.

Table 11.2 Issues commonly raised in interviews and CQC reports as related to the right to privacy model

Privacy topic	**Exemplary issues relating to key factor 1: Suitable space and amenities**	**Exemplary issues relating to key factor 2: Residents' choice and control**	**Exemplary issues relating to key factor 3: Positive relationships with care workers and managers**
Residents' physical space in the care home (My space)	Single/shared bedrooms; Extra lounge; Accessibility of toilets and bathrooms.	Choice and control over decoration and furniture.	Care workers respecting residents' private space and belongings.
Residents' choice around how to spend their time and structure their days (My time)	Availability of personal rooms and a range of communal areas, that can be easily accessed.	Choice to retire to personal space or spend time in communal areas; Availability of activities and choice to participate.	Care workers make a personalised care plan, recording wishes and preferences; Care workers respect residents' decisions and choices.
Residents' care (My care)	Have a private space for personal or healthcare to be administered.	Choice over who administers the care. Choice over personal and medical care.	Respectful and trusting relationships with care workers, who provide care.
Residents' personal data and information (My information)	Suitable spaces and hardware to keep personal data locked and stored safely; CCTV cameras in the care home.	Residents' choice over the use and sharing of personal data.	Respectful treatment of personal data and information.
Residents' families and relationships	Spaces to host family and friends and to spend time alone with	Choice over how and where to spend time with family and friends;	Behaviour when friends and families are around; Plans around

with people outside the care home (My family)	visitors; Amenities to stay in touch with family and friends, such as wireless connection and phones.	Volunteers coming into the home; accessibility to advocacy services.	enabling couples to have intimate relationships.
Residents' bodies and physical appearance (My body)	Spaces and amenities to care for the physical appearance of residents; Spaces for intimacy.	Residents' wishes over their own sexuality; Residents' wishes regarding personal appearance.	Respect over residents' physical appearance; Openness/non-discriminatory towards residents' sexual orientation.

11.4 Good and poor privacy practice in care homes

This section focuses on good – and, at times, poor – privacy practice in care homes from the perspectives of CQC inspectors and the participants in this study. The interview participants framed most of the "right to privacy" topics that they picked up on in terms of statements about good and poor privacy practice. The CQC and interview participants mentioned similar practice points; nevertheless, the findings for each group are reported separately to ensure that the voices of all participants are heard.

11.4.1 Good privacy practice as reported in CQC inspection reports

As explained in Section 10.2, most of the CQC inspection reports mentioned good or poor practice points when referring to "privacy" or "the right to privacy". Some inspection reports did not mention privacy or the right to privacy but reported on related concepts, such as autonomy and dignity or respect. All the good and poor practice points fit under at least one of the six privacy topics and three key aspects. More good practice points were reported than poor ones. In this section, the focus is on outlining good privacy practice according to the analysis of the inspection reports. Where appropriate, poor privacy practice examples are reported. These were often more specific than the good practice points.

Top 3 good practice points in inspection reports

The inspection reports included a wide range of good practice points. Some points were mentioned frequently, but most were mentioned fewer than five times. The following list contains the three good practice points that were mentioned most frequently (by 15 or more inspectors in their reports). Privacy practice points mentioned by the CQC expert interviewees are also included. In contrast with the inspection reports, the experts tended to phrase practice points in terms of poor rather than good practice.

1. Knocking on doors and waiting for permission to enter: The most commonly mentioned practice point in the CQC data analysed for this study was knocking on residents' bedroom doors and waiting for permission to enter (n=38). This issue, which was frequently mentioned not only in the inspection reports but also by the interview participants, fits under privacy topic 1 (residents' physical space in the care home) and key aspect 3 (positive relationships between care workers, residents and relatives). The following statement illustrates this:

> Care staff recognised the importance of not intruding into people's private space. We saw them knocking and waiting for permission before going into people's bedrooms. (Care Home Report, Good, 029)

One report noted that this practice had not been followed during the inspection, which was a poor practice point.

> People were not always treated with dignity and respect…. We… observed on two occasions, staff members entered people's bedrooms without knocking. (Care Home Report, Inadequate, 099)

One of the CQC expert participants commented that it is poor practice for care workers to knock on doors and then immediately enter. Rather, they should wait to be invited in. The following statement highlights this:

> We will do tours of the home when we go and I've seen staff knock on doors and walk in and somebody's been in bed or staff have been helping with personal care and it's like, well you didn't wait. (CQC, expert 3)

2. Secure storage and respectful treatment of personal data: The second most common good privacy practice point (n=15) was to store personal information securely and keep it confidential. Six inspectors reported poor practice points in their inspection reports when care homes had not kept personal information private. This practice point, which sits under privacy topic 4 (residents' personal data) commonly overlapped across two key factors: the physical and electronic storage of information (key factor 1, availability of suitable space and amenities in the care home) and care workers respecting confidentiality (key factor 3, positive relationships). The following statements noted good practice:

> Information about people was kept securely in the office and the access was restricted to senior staff. When staff completed paperwork they kept this confidential. (Care Home Report, Outstanding, 002)

Poor practice examples often pointed to specific actions or a lack of suitable storage for personal information. For example, in some instances care workers discussed residents' personal information in public spaces, where third parties might have overheard:

> People were not always treated with dignity and respect. We observed staff members discussing one person in the doorway of their bedroom where the conversation could be overheard by other people in the service. (Care Home report, Inadequate, 088)

In another instance, personal information was displayed on a whiteboard in a public area and no secure storage was available.

> The [care home's] office was frequently left unlocked and unattended which meant people's private information could be accessed by people and visitors passing in the corridor. (Care Home report, Inadequate, 091)

> We found a notice board in a communal area displayed personal details of people including listing their individual care needs. (Care home report, Inadequate, 093)

One of the CQC experts interviewed mentioned a situation in which care workers had handed a resident's mail to their family. She felt that this was bad practice. Rather, care workers should have asked for the resident's consent to hand over their private correspondence.

3. Close and lock doors during personal care: The third most common privacy practice point (n=16) was closing or locking doors when care workers were providing personal care, such as support with personal hygiene. This issue falls under privacy topic 3 (residents' care) and key aspect 3 (positive relationships). The statements resembled the following:

> During the inspection we noted staff respected people's privacy when delivering support. For example we observed bedroom and bathroom doors were closed when personal care was delivered. (Care Home Report, Requires Improvement, 075)

> People's right to privacy and dignity were supported by staff in the provision of care and support. Personal care was given in locked bathrooms or people's own en-suite facilities. (Care Home Report, Good, 031)

According to one CQC expert, using privacy screens in communal areas when providing personal care is not a suitable alternative to providing that care in private bedrooms. The expert felt that in public spaces, privacy could never be protected as much as it could be in private bedrooms. However, if residents explicitly consented to receiving care behind privacy screens, this could be acceptable. This emphasises the relationships between key aspects 2 and 3 under privacy topic 3 (residents' care).

> There were screens in the lounge area [referring to a care home], sort of cut off by hospital-type screens and I said, why are those screens there? And they said, well, a couple of the... when the district nurses come or the podiatrists come, they want to see people in the lounge and we just screen them off, and I was like, really? That is not appropriate. Why aren't you telling professionals that, actually, they need to ask people to go to their bedroom? (CQC, expert 5)

Other good privacy practice according to the CQC

Besides the top 3 privacy practice points, many others were noted in the CQC reports. Most practice points were good ones. Table 11.3 summarises those practice points and links them to the relevant privacy topics and key aspects.

Table 11.3 Summary of privacy good practice points in CQC inspection reports

Privacy topic	Key aspect 1	Key aspect 2	Key aspect 3
Residents' physical space in the care home	Residents have single bedrooms with lockable doors; There is a range of communal areas including a garden and dining area; Amenities include internet access.	Residents can personalise their own rooms and choose to lock their door; They can also express their preference over whether they wish to have their doors open or closed.	Care workers and other people knock on residents' doors and wait for permission before entering.
Residents' day and night time	Residents have several spaces available in the care home, including private bedrooms, in which they can spend their day and night and appropriate spaces for religious practice.	Residents can choose to spend time alone in their private rooms or socialise with whom they wish; They have the option to eat in their bedrooms and they can follow their religious	People in the care home get to know residents' life stories, favourite past times and habits through a personalised care plan. They support residents in making choices and respect

		beliefs in the care home environment; They have a range of activities available to them and can choose to participate if they wish.	these choices through appropriate communication, for example by making available “do not disturb” signs for doors.
Residents’ care	Rooms are available in which personal care can and will be administered; Bathroom and toilet facilities have lockable doors and windows with curtains, that can be drawn when in use; Privacy screens are available in the case they become necessary and care workers have all necessary workable equipment, such as hoists and blankets, for personal care.	Residents get the choice over the sex of the care workers providing personal care.	Care workers administer personal care only behind closed/locked doors; They discreetly ask residents if they feel like they need support, especially when the resident is in a communal area, and explain to the resident any procedure they are about to carry out; They cover residents’ bodies during personal care; Care workers refer to residents by their preferred name.
Residents’ personal data and information	Residents’ personal data is stored in secure locations and is only accessible to those people directly in charge of the care of a resident.	No good practice point mentioned in reports.	Care workers and other staff discuss residents’ personal issues discreetly i.e. not in public or communal areas, such as hallways or with open doors; Personal information does not get shared automatically with family members or people not directly involved in the care of a resident.
Residents’ families and relationships with people outside the care home	The care home has suitable facilities for residents to entertain visiting family members and friends, such as private sitting rooms; Residents have the opportunity to make phone calls any time that no one else can overhear.	Residents and their families have open visiting times in the care home; In care homes with shared bedrooms, the care home will seek out residents who wish to share bedrooms with others; Residents can access their bedrooms or quiet communal areas to spend time alone with family and	Care workers and others knock on residents’ bedroom doors and enter only with permission.

		friends; Residents are able to nurture or develop romantic relationships.	
Residents' bodies and physical appearance	The care home makes available spaces and amenities for hairdressing, nailcare and the care of residents' clothes.	Residents can choose to have time for intimacy and get support in maintaining sexual relationships if they wish.	Care workers promote residents' independence in washing and bathing themselves as much as possible; Care workers ensure that residents are dressed in clean and fitting clothes, hair is brushed or groomed and generally residents appear well groomed and clean; Care workers cover residents' bodies when providing personal care as much as possible; They close and lock doors and curtains when providing personal care.

11.4.2 Good privacy practice from the perspective of residents, relatives, care home managers and care workers

In the interviews, all the participants were invited to share what the right to privacy meant to them in a care home context. Some issues and privacy practice points recurred across the participant groups. However, different participant groups focused on different privacy topics and key aspects. These are now presented for each participant group.

Care home managers

All the care home managers mentioned good privacy practice points. Regarding privacy topic 1 (residents' physical space in the care home), three managers referred to knocking on residents' doors or asking for permission to enter as a "basic" good privacy practice point. They felt that this showed respect for the residents' personal space. The following statements illustrate this:

> The right to privacy, at a basic level, is that nobody just walks into your room without knocking… (Participant 104)

> Carers can't just assume that they go into somebody's room without knocking. (Participant 101)

> It shouldn't be deemed as I can go into their room without knocking or asking permission. It's their space and should be respected for it. (Participant 103)

A fourth manager also referred to residents' physical space in the care home and residents' family life as aspects of privacy. She felt that it was good privacy practice to make available suitable spaces for married couples to be together in the care home:

> I give them (the married couples) two rooms. So they have one room as their bedroom and we give them another one as their private sitting room. It just enables them to remain as a married couple and spend as many hours as they wish still as just a unit together and not really encompassing a lot of space and time with other people. (Participant 102)

One care home manager also mentioned privacy topic 2: residents' day and night time. This manager felt that good privacy practice means that residents can choose to stay in their private bedrooms, including during mealtimes:

> That is in their [a resident's] room and they don't have to come out. Is it around mealtimes, we don't just assume that everybody wants to eat in small dining rooms. (Participant 104)

This manager explained that care home staff were responsible for ensuring that all potential privacy issues were considered in a care plan. To this participant, knowing the resident is the foundation for being able to maintain that resident's right to privacy. This cuts across all privacy topics:

> It's exploring all options and [potential issues] what is important to somebody doing an initial assessment… Do you like company? Choice and privacy go hand in hand. Do you like to go to bed early?... Privacy is all of those little things. (Participant 104)

This participant also highlighted that it was important to immediately address breaches of privacy:

> Privacy in the home what it means to me is if anybody sees anybody just walking into anybody's room, they need to address it straight away. (Participant 104)

Care workers

The care workers referred to several good practice points when invited to share their views on what the right to privacy meant to them in the care home. They also mentioned dilemmas and difficulties with regard to maintaining residents' privacy; these are discussed in Section 12.5.

When discussing good practice, most of the care workers – similar to participants in other groups – spoke about the need to respect residents' personal space (i.e. their bedrooms). This falls under privacy topic 1: residents' physical space in the care home. Many care workers felt strongly that residents' private bedrooms were their personal space with their own belongings, and that residents should be able to do as they wish in this space. Respecting residents' space, according to the majority of the care workers, again entailed knocking on people's doors before entering and waiting for permission to enter. The following statements exemplify this view:

> [The residents] do like their privacy. You don't go barging into their rooms and things like that. (Participant 304)

> Entering anyone's room, you always have to knock, whether they're going to be in bed or out of bed, you don't just barge in, so, I wouldn't like for someone just barging into a room where I was, so you learn to do the same. (Participant 314)

> Good practice, to knock on the door before you enter the room and wait to be asked in. (Participant 313)

Most care workers also picked up on issues related to privacy topics 3 (residents' care) and 6 (residents' bodies and physical appearance). All the key aspects played a role in many of the statements on these topics. Most commonly, care workers mentioned the good privacy practice of closing doors and curtains when providing personal care, covering residents' bodies and explaining to residents any procedures that they are about to experience. Often, care workers also spoke about procedures when residents are using the toilet. This included locking the doors and having buzzers available. The following statements provide examples:

> You'd knock on the door, you wouldn't just walk in the room. You'd let them know who you are. You don't just pull the covers off them, you tell them what you're doing and keep them covered up. If they're on the toilet, cover them up, you haven't got to be sitting there naked, you know. Leave them to go to the toilet and they have a buzzer outside the door. (Participant 308)

> When they [the residents] need the toilet, we have to lock the door so no one can walk in, shut the curtains, if they're on the commode, in their bedroom because obviously people walking past the window you don't want them to look in. (Participant 303)

> So you know explain to the person what you are going to do and 9 out of 10 you will be quite lucky and the person will just say “oh I don’t care”. (Participant 315)

Some care workers also spoke about providing privacy in communal spaces. One participant mentioned that using screens in communal areas can help to maintain residents’ privacy; for example, when they are being hoisted in or out of a chair:

> Going back to using privacy screens. So somebody is using a hoist in a communal area. Just to shield that person from everybody’s views but giving them the option... (Participant 317)

One participant mentioned residents’ wish to choose the gender of the care worker who will provide their personal care. This participant felt it is good privacy practice to give residents the choice:

> Sometimes some of the female residents prefer a female carer than a man and they have refused to have a man, which is entirely up to them… there is always a female carer on shift. (Participant 306)

Many care workers also related good practice points to topic 4 (residents’ personal data and information) and key aspect 3 (positive relationships). Many of the issues they brought up were intertwined with other privacy topics. Some care workers said it was their duty not to share personal information freely and to protect confidential information. In practice, this meant not sharing information with third parties, speaking to residents discreetly about sensitive topics (such as personal care needs) when they are in communal areas, and ensuring that residents could have private conversations with healthcare professionals. The following statements illustrate this:

> If nurses or doctors or any professional assessors people come in to talk to the resident or their family that they have got a private room to do that and it’s not happening in the main communal spaces. Ideally in the person’s own bedroom or if you are gonna use one of the communal spaces like the dining room or the lounge you make sure that it is closed off and that people know not to disturb. Putting a sign on the door saying absolutely do not disturb so that people can have those conversations with the doctor or nurse or have dressings done. (Participant 317)

> You must respect your residents. They need to know they can trust you. You are not going to tell someone down the road what you had seen this morning. (Participant 313)

> You have to work under the Data Protection Act. You don't give out that person's private information… In a care home sometimes, you have got a lounge of people, "Here you are, [name of a resident], do you need the toilet?" The whole lounge has heard… All the lounge didn't want to hear that. (Participant 313)

Some care workers mentioned that the right to privacy also affects residents who have recently died. They felt it was important to use privacy screens when transporting someone who has died through communal areas and to lock that person's bedroom door to protect their belongings until family members could collect them.

Care home residents

In the interviews with care home residents, a large number of good and bad privacy practice points were mentioned. Privacy topic 1 (residents' physical space), key aspect 1 (availability of suitable space and amenities in the care home) and privacy topic 2 (residents' day and night time) were widely discussed together in terms of good practice. Most of the residents appreciated having personal en-suite bedrooms with amenities such as buzzers and private patios, in addition to several different communal areas. They felt it was good practice that they were able to choose to spend time alone in their rooms doing as they wished or to mix with other people in the communal areas:

> We all have our own rooms, so you can certainly go into your room without any worry at all, and be on your own if you want to. (Participant 201)

> We've got our own en-suite so we can do what we like and have a nice bath or a shower, whatever. It's nice. (Participant 209)

Many residents also mentioned that care workers respected their space by always knocking on doors before entering:

> They've [referring to care workers] got to be able to come in and go when they want, really. They always knock at the door first. (Participant 205)

> I have got the privacy here, yes. Everybody knocks at the door before they come in. Then they come in and we have a chat. (Participant 206)

However, during one interview a participant had just explained that care workers always knocked when a few minutes later a care worker walked into the room without knocking or asking for permission to enter. When the participant was invited to share how she felt about this once the care

worker had left, she said that she appreciated care workers feeling so comfortable around her that they felt able to just walk in.

One participant also shared a negative privacy practice point in this regard. She felt that care workers checking on residents at night disturbed her privacy, especially when she did not know what time they would come in. This again emphasises the importance and interrelatedness of key aspects 2 and 3, as the resident could not choose the time when the care workers came in:

> Of a night we have people just open the door to see if you are in bed or what… Sometimes well you don't know what time it is going to be… It's not like you are staying awake for them but… They pop their head round and I said to them, "I don't need you to". (Participant 210)

Some residents also spoke about the privacy topic of personal care. They felt it was good practice that they were covered when receiving personal care and that care workers left them alone in the bath and encouraged them to wash themselves:

> This man I've had, he always says, "I'll leave you now for a few minutes in the bath on your own", not on your own but he'll be doing something else. You wash your private parts and that sort of thing. I respect him for that sort of thing. (Participant 210)

> Participant: They sort of cover you up when they are doing you and washing you and getting you ready for bed and things like that.
> Interviewer: That is something you appreciate?
> Participant: Yes. (Participant 204)

Other residents spoke about privacy topic 2 (residents' day and night time) and privacy topic 4 (residents' family life). They felt it was good practice that activities were available in the care home, which they were encouraged and could choose to participate in. They could also choose to invite visitors to the care home and spend time with them without being disturbed:

> I have visitors if I want them and I am quite happy. (Participant 206)

> Privacy to me means basically able to only see people you need to see like visitors who care for people and that. (Participant 208)

> If we're going on an outing… if you don't want to go and the carers think it's a good idea for you to get out, you wouldn't be made to do it. If you said, "I really don't want to go", they would respect that, but they would encourage you by saying, "You know, you might enjoy it, and it's nice for you". (Participant 202)

Regarding personal information, two participants felt it was good privacy practice that their personal information was not shared with anyone else in the care home:

> I like to be able to talk to somebody, but then know it's private… There's always something you want to talk about and you'd like to know that it stays confidential. (Participant 209)

Relatives

For many of the relatives, good privacy practice points in care homes related to privacy topic 1: residents' physical space in the care home. The majority thought that maintaining the right to privacy in a care home meant having private bedrooms:

> They [the residents] have got their privacy here anyway as we said, separate sitting room, separate bedroom and bathroom for themselves. (Participant 410)

> She [the relative living in the care home] has got her own bedroom. (Participant 405)

One relative mentioned the need for care workers to knock on residents' bedroom doors before entering. Another said it was good practice that residents could choose to have their doors open or closed.

Another relative mentioned a practice point relating to privacy topic 2 (residents' day and night time), key aspect 2 (ensuring residents' choice and control). This relative felt that it was good practice for her parent to be able to choose to stay in bed:

> She could stay in bed if she wanted to. There is no force there saying of come you have got to get up. (Participant 405)

One relative also mentioned that it is good privacy practice when care workers explain to care home residents what kind of personal care they are going to provide.

Table 11.4 presents the three most commonly mentioned privacy practice points for each participant group.

Table 11.4 Top privacy practice points per participant group

Participant group	No 1 privacy practice point	Privacy topic/key aspect	No 2 privacy practice point	Privacy topic/key aspect	No 3 privacy practice point	Privacy topic/key aspect
Managers	Knocking on residents' doors and waiting for permission before entering.	Topic 1/KA 3	Providing suitable spaces and amenities to care home residents.	Topic 1/KA 1	Knowing residents through detailed care plans.	Overarching
Care workers	Knocking on residents' doors.	Topic 1/KA 3	Locking rooms and covering residents' bodies during personal care.	Topic 3/KA 1 and 3	Talk to residents discreetly about personal care needs in communal areas.	Topic 3/KA3
Residents	Residents have their own private bedroom. They can choose to spend time in it alone or mix with others. Care workers respect their space by knocking on doors.	Topic 1/KA 1,3	Residents can choose to participate in activities and invite visitors to the care home.	Topic 2/KA 2	Care workers do not share private information with third parties.	Topic 5/KA 3
Relatives	Residents have private bedrooms.	Topic 1/KA1	Residents can choose to stay in bed.	Topic 2/KA2	Care workers explain to residents what procedures of personal care they are going to undertake.	Topic 3/KA3

11.5 Privacy dilemmas

Some participant groups, especially the care workers and managers, mentioned dilemmas in the context of privacy practice in care homes. These were mainly difficulties in balancing issues around privacy, residents' safety and relationships with relatives. Often, participants explained how they dealt with these dilemmas on a day-to-day basis.

11.5.1 Residents' safety

The safety of residents, especially when alone in their bedrooms, was a concern for many care workers and one care home manager. These participants often referred to their employer's regulatory and legal duties, which affect residents' privacy. They also mentioned specific practice points relating to residents' physical space or their private information. For example, one care home manager felt that having to check on residents at night violated residents' right to privacy. This correlates with one of the resident's statements. The manager said:

> One of the rules I am finding difficult to implement but we are told we have to. And that is every hour, during the night we go in [to residents' bedrooms] and check on people. There is lots of residents here who hate it. They say "I don't want anyone coming in every hour checking hour". God forbid, if we didn't and we found somebody laying in a pool of blood in the morning because they had fallen and we haven't gone in and checked, we can't win can we… In their own homes, no one would check on them. (A care home manager, participant 102)

Another care worker felt that staff must be able to enter the bedroom if a resident has had a fall. This means doors cannot be fitted with locks and residents cannot choose to lock their doors, which could go against good privacy practice under key aspect 2 of privacy topic 1:

> If there is someone on the floor, you have to go in and I mean... we can't have locks on the doors or anything like that. They can't lock themselves in, thank god, because I think a lot of them would do which would cause a lot of problems. Obviously, for their own safety. (A care worker, participant 307)

Given that many participants mentioned that it was good practice to knock on people's doors and wait for permission to enter, the care workers were invited to share what they would do if there was no answer from inside. One participant highlighted the importance of knowing residents and their habits, and not simply walking away if there was no answer:

> Certainly the expectation would be if the member of staff knew the residents they would know whether this resident would or wouldn't answer… There will be those who don't immediately answer and to then open the door a little bit and announce yourself. (Participant 315)

Another care worker said that she used a risk assessment to make decisions about whether to overrule someone's privacy for their safety.

A further safety matter frequently mentioned in the interviews concerned residents' private information and conversations. Some care workers explained that they try to keep residents' private conversations confidential but that they occasionally have to share it with colleagues for safeguarding purposes. They tend to make their own judgements on the seriousness of the information before sharing:

> Like someone can say, "Last week my daughter come in and I was really unhappy", I wouldn't then have to go forward necessarily, whereas say, for instance, "I don't want to be here" – not that anyone ever has – but if they said something what was worrying and I was concerned about, I would then have to overrule the privacy in that sense to go to a senior or management, or say a member of staff, anyone can tell you something, and to a certain point of it you can keep it private, but you have got to safeguard what's right. (A care worker, participant 310)

> If it's really serious [what residents have told care workers] you have to go and talk to the care home and report everything. (A care worker, participant 310)

11.5.2 Relatives, visitors and the right to privacy

The interview participants mentioned that relatives and visitors could pose privacy dilemmas. One the one hand, visitors may be the cause of residents' privacy being violated because they do not follow the same good practice as people working in the care home. One care worker shared the following story:

> We had a resident many years ago. He was a man who wanted to be a woman. We had to respect his privacy and he wore dresses in his room… I had a little eight-year-old come running down one Saturday afternoon to me, shouting "[Name of participant], so and so has got dresses on". You [referring to the eight-year-old] have just told the whole lounge. (A care worker, participant 313)

On the other hand, many participants implied that sometimes care workers could be violating residents' right to privacy in order to accommodate relatives' concerns about their family member's safety and well-being. In one case, for example, a care worker said that she documented a resident's sexual activity to avoid criticism from the family:

> There was just a case that a resident didn't want to get dressed because he was masturbating. I told the carer to document it for the family because you don't later want to hear from them, "Why isn't he dressed?" (A care worker, participant 305)

11.5.3 Lack of knowledge about good practice

One care worker explained that she did not always know about good privacy practice, which placed her in difficult situations. For example, she sometimes did not know whether or not she was required to knock on residents' doors:

> Some of the independent ones like if they are getting like washed and dressed or they are doing something in their rooms and you just walk in and it's like, you don't know whether to – sometimes they are like, no, you could have stayed in here and then I feel like maybe I should step out the room and knock. (Participant 312)

11.5.4 CCTV cameras

Only one care worker spoke about CCTV cameras in the care home, and only after being prompted by the researcher. No one mentioned this topic unprompted in respect of privacy; however, one CQC expert pointed the researcher to relevant statements on the CQC website.

The care worker who spoke about surveillance in the care home felt that CCTV cameras may violate residents' privacy, especially when they are fitted by families in their relative's bedroom without the knowledge of care home staff:

> The family can just literally come in and put a camera in the room [resident's bedroom] and they don't have to tell us… There is no monitoring of it… I was a resident – I know, for a fact if it was my mum or dad, my mum and dad would say, "I don't want people seeing me. I don't want it all being filmed me being washed and dressed." I think they would say "Don't put a camera in here". (Participant 307)

11.5.6 Barriers to innovative solutions and lack of support from external organisations

Some participants explained that they had tried to find innovative solutions to privacy dilemmas but had perceived barriers when approaching local authorities and the CQC. These included a lack of

openness, ageism and difficulty in balancing safeguarding concerns. One manager mentioned a resident who had particular sexual needs. The manager and staff identified this as 'a matter of human rights' and put in place various mechanisms to respect that right, including designated times when the resident would be left in private. The care home also tried to reach out to the local authority for support, but felt that there was none available:

> We have got a resident in his 90s and he is still very sexually active... we even approached the local authority to see whether there was any support that was out there for older people to meet their sexual needs…There isn't. (Participant 104)

Furthermore, a person who was external to the care home reported a member of staff to the CQC over a concern raised regarding this resident. The care worker subsequently had to leave:

> [The care worker] was talking to her flatmates about [possibilities to support] the resident without naming him and they reported her and raised it as a safeguarding. She had to go. I couldn't understand that... I didn't understand the local authority's view on trying to meet the needs of somebody. (Participant 104)

11.6 SUMMARY

This chapter presented the findings on the right to privacy in care homes from the perspectives of the CQC and people living in, working in and visiting care homes. It also discussed some of the literature on the concept of privacy. A common theme that emerged from the interview data provided by the CQC experts, care home managers and care workers was the association between *privacy* and the concept of home, and the association between *the right to privacy* and relationship boundaries between people living and working in care "homes". This provided the basis for the right to privacy in care homes model, in which six privacy topics define the dimensions of privacy in the home and three key aspects define the right to privacy as a relationship-structuring concept. One of the key aspects is not about relationships *per se* but environmental factors that need to be in place in order to build relationships that respect the right to privacy.

Furthermore, the interview participants and CQC inspection reports provided some good privacy practice points. Many of these were mentioned by all the participant groups. Also highlighted were some privacy dilemmas, which care workers, managers and residents faced on a daily basis. These dilemmas were mainly related to safety concerns and to relatives (and other visitors to the care home) not following the same privacy good practice points.

12 Discussing the right to privacy model

In Chapter 11, the findings of the study on the right to privacy were reported. The research questions for this element of the study were as follows:

- What is the evidence for good practice in protecting care home residents' right to privacy?
- What, according to study participants, is necessary to protect the right to privacy in a care home setting?
- What, according to CQC inspection reports and other relevant documents, is "good" and "poor" privacy practice in care homes?

This chapter summarises the findings and discusses them in the light of the typology of perspectives (see Chapter 10). In addition, it discusses the potential contribution to the literature on evidence for good privacy practice. This is based on the indicative material collected from the CQC inspection reports and the perspectives of people living in, working in and visiting care homes.

12.1 Conceptualising privacy and the right to privacy in care homes

Rights-grounding, value-based associations between human rights and care homes often allowed the participants to discuss these in their contexts and pin down specific practice points. The concept of privacy had the same effect on many participants of this study; ultimately, this made it possible to create the right to privacy in care homes model. The findings presented in Chapter 11 suggested that are two aspects to privacy: the concept of privacy and the right to privacy. These two aspects can be associated with the concept of home. A care home is a form of home that comes with distinct relationships and features; it cannot replace experiences in previous homes but signifies a new stage in life. The concept of privacy in relation to the context of home is multi-dimensional, and the dimensions were translated into six privacy topics emerging from the data of this study. The right to privacy, on the other hand, is a tool for setting boundaries in the relationships between care home residents and care staff. These were translated into three defining key aspects and corresponding good and poor practice points. Together, the six privacy topics and three key aspects become the right to privacy in care homes model.

Solove's (2008) criticism of attempts to conceptualise privacy, and his own four-dimensional theory of privacy, were discussed in Chapter 11. Although this research did not use Solove's theory as a guiding framework, it can be used to scrutinise the right to privacy in care homes model.

The model that emerged from this thesis is a framework for understanding and practising privacy in care homes for older people in England. It was developed from the bottom up, based on the voices

of people in care homes and care home regulators. The six privacy topics capture a plurality of dimensions. The focus is on the link between privacy and home, considering care homes as homes. The topics and dimensions are flexible enough for interpretation, and new ones could be added. This model is in line with Solove's theory of privacy. Therefore, this thesis makes two additions to the literature on privacy in care homes. First, it contributes a framework that can be tested by future research aiming to determine privacy in care homes. Second, it defines ideas that relate to privacy as a concept and the right to privacy as a matter for human rights: something that other contributions have not defined.

There are potential criticisms of this model. The first is the concept of the home as a focal point. The idea of home has been defined in many ways: some definitions focused on the home as a building and physical space, and others defined it as a place where there are caring relationships (Rijnaard et al., 2016). In the literature on "homeliness" and the sense of home in the context of care home residents, privacy is often defined as a key aspect, rather than an overriding consideration that is at the core of the home. In other words, privacy is not the only factor that makes a home "homely" in that literature. For the purposes of this thesis, however, a home is defined by the concept of privacy and the topics and practices that emerged from the findings.

Furthermore, the model could be criticised for being too "privacy-centric". The six privacy topics cover most aspects of life in the care home. The prominence of the right to privacy may be seen as being at the expense of other human rights that could be relevant to each of the privacy issues. Regarding the issue of "my body", for example, the right to be free from inhumane and degrading treatment is as relevant as the right to privacy. However, this study does not aim to prioritise the right to privacy over other human rights in care homes. Rather, the right to privacy, as argued by the CQC, is significant in many areas of life for care home residents and staff. Through interaction with other human rights, it can establish relationship boundaries.

The suggestion that such boundaries could be defined through good and poor practice that applies to all may also attract criticism. The right to privacy is often considered elusive in its exact scope for application in the courts, in regulation and in practice; thus, it is flexible enough to accommodate individual cases (see Chapter 11). Producing a list of good privacy practice points may imply that such practices can be determined, perhaps at the expense of this flexibility and individual preference. However, this study does not claim to have produced an exhaustive list of rules to follow to ensure that the right to privacy is respected. Neither does it claim to have produced an interpretation that could withstand legal scrutiny. Rather, good practice ideas (some of which were shared across the participant groups) can provide guidance that takes into consideration the legal

and normative requirements to act a certain way. The findings suggested that guidance was important to some care workers, who at times used the "Mum test" to steer their actions. Furthermore, the three key aspects in the model include residents' choice; therefore, in theory, individual choices made by residents shape privacy practice under the privacy dimensions.

The following sections discuss the right to privacy in care homes model by considering the typology of perspectives. The discussion focuses on three broad categories, rather than each perspective.

12.2 The right to privacy model in care homes: the typology of perspectives

12.2.1 Social, political and adult social care perspectives

The perspectives included in this category approached care homes as institutions with potentially negative and positive effects on residents' human rights. These perspectives propose that human rights can be a tool to acknowledge, highlight, discuss and find solutions to general human rights issues related to care homes in society. Human rights can also play a role in recognising care homes as potential rights-enabling environments for older people.

The idea of a care home as a home for residents, including the six privacy topics that relate to home, emerged from the associations that many of the participants made between the human right to privacy and care homes. The right to privacy in care homes model could contribute to this category of perspectives on several levels. Firstly, it could be the foundation for an in-depth analysis of potential problems related to privacy in care homes for older people, providing a structured approach to critically engage with this type of adult social care service and any alternatives. Indeed, one participant, who took the anti-institutional perspective, associated life in a care home with a violation of the right to privacy. According to this participant, living with strangers and following a daily routine of care activities does not allow for privacy. The model could help to frame and address these topics.

Secondly, the model could build a bridge between the anti-institutional and the rights-enabling perspectives by re-framing care homes as new homes for older people. This could reduce perceptions of care homes as risky institutions and help to re-envision them as alternative homes. This idea is not new; various academic studies have focused on the homeliness of care homes and what makes a care home a home. However, linking care homes with homes has been criticised (Peace and Holland, 2001). As Davies and Brown-Wilson (2007 p. 65) have pointed out: "Many commentators have questioned the appropriateness of attempting to make care homes like 'home's even if it were possible given that home is usually associated with family, shared memories and comfortable familiarities". According to these authors, homes are mostly privately owned or rented,

whereas care homes are owned by someone else. Homes are domestic, whereas care homes are communal and institutional. Life in a private home is not regulated, whereas life in a care home is (Peace and Holland, 2001). Peace and Holland thus argued that envisioning care homes as homes has "run its course", as they are incompatible on several levels.

In fact, most of the residents and relatives in this study did not make associations between home and the right to privacy in care homes. The relevant statements suggest that a root cause for residents was their emotional connection to their previous homes. For relatives, concerns about the safety and well-being of their parents, grandparents or older friends appeared to override privacy considerations. However, the potential for re-envisioning care homes as homes – from these perspectives and considering the human right to privacy – depends on how the concepts, including that of home, are defined and approached.

12.2.2 Law-oriented perspectives

The participants who took a law-oriented perspective either considered that human rights has no role as a legal concept in care homes or viewed it as an avenue for seeking legal redress for violations of those rights.

Under the CQC's regulatory framework, care homes must maintain residents' privacy (see Chapter 11). Care homes have a grade 1 direct legal liability under the HRA and a grade 3 liability under other laws and regulations that are relevant to privacy, including the Data Protection Act 2018 (see Chapter 4). Furthermore, the right to privacy is a broad legal concept that potentially covers many aspects of an individual's life, and this makes it notoriously difficult to pin down what it involves in practice (Tugendhat, 2017).

One objective of this study was to develop a model that provides a better understanding of the practical meaning of the right to privacy in care homes. Here, the right to privacy is protected and respected by normatively structuring relationships in care homes in line with the three key aspects of privacy Only a few participants mentioned the right to privacy as a legal concept. However, in theory, under the legal and regulatory framework it could be possible to seek legal redress for many breaches of the key aspects in all six privacy topics in the model.

Given the good and poor practice points identified and the potential difficulties in gaining access to legal recourse, the question arises as to which avenues are the most useful for care home residents and their families in cases where the right to privacy is violated. If we consider the right to privacy as a relationship-structuring concept (as proposed in this thesis), we can seek answers to this question not only in the legal system but also in the care home community. All the participants contributed

ideas about good practice points. Many of these were in agreement; notably, there was a consensus on the need to knock on someone's door and be invited in before entering their private space. This suggests that the concept has already taken effect – at least in theory – on relationship structures. These relationships produce standards for interactions inside the care home, which are enforced by the care home community, especially managers. Many residents and relatives commented on their care home manager's ability to find solutions to perceived injustices. Furthermore, many of the CQC documents mentioned the value of and need for internal complaints and whistle-blowing mechanisms.

The right to privacy in care homes model is an example of how a human rights lens can help us understand how to protect and respect rights inside care homes, keeping legal action as a last resort. It also highlights the significance of internal mechanisms and access to advocacy as alternatives to the formal legal system.

12.2.3 Normative practice shaping perspectives and the whole-system approach

In these categories the equal rights, issue-based, care practice and organisational ethos perspectives are included. The implications of the right to privacy in care homes model on the whole-system perspective are discussed in this section as well. This is because the model blurs the lines between the perspectives, including the points discussed under the law-oriented and adult social care approaches. Privacy already plays a role in the human rights framework governing English care homes and is widely considered as a factor in providing high-quality care services (see Chapter 11). Therefore, privacy has already been systematically integrated into the definition and regulation of high-quality care, which is a defining factor for the whole-system perspective.

In line with the equal rights perspective, most of the participants in this study acknowledged care home residents as equally entitled to privacy, which can be interpreted to extend to the right to privacy. The stories shared by the participants and in the CQC reports highlighted not only potential challenges to maintaining privacy but also ways to navigate them, thereby defining practice points. Here, the equal rights, issue-based and care-practice-shaping perspectives are linked. Even in the face of ethical dilemmas, the study suggests that recognising the importance of maintaining privacy encouraged care home staff to find innovative solutions. Such solutions also required flexible thinking in people inside and outside the care homes, including relatives and local authorities. This adds to the discussion on value-based communication (see Chapter 10, section 10.2), which mentioned that value-based associations with human rights could encourage practical thinking in study participants.

The six privacy topics cover many different areas of life and work in care homes. Therefore, maintaining privacy becomes a matter of organisational ethos. Importantly, the privacy model highlights that privacy and the right to privacy are multifactorial. They transcend care workers and care practice and are also matters for residents, visitors and the wider community, including the CQC and local authorities – thus, the "whole system". At the same time, important for maintaining privacy are not just relational factors but also environmental ones, including the availability of suitable amenities.

12.3 SUMMARY

This chapter discussed the right to privacy in care homes model in the context of some theoretical considerations and the typology of perspectives. It proposed viewing care homes through a "home" lens in order to contextualise, explore and understand the concept of privacy and put it into practice. The potential role of the right to privacy is to structure relationships in the home. The typology of perspectives provided the basis for a discussion on the possible value and implications of this model. The discussion proposed that a systematic approach to maintaining privacy requires a multi-stakeholder recognition of obligations in addition to the flexibility to accommodate innovative solutions. It also argued that environmental factors can be as important as relational ones. Finally, it highlighted the potential value of internal grievance mechanisms in care homes as an alternative to the courts as the first avenue for seeking redress in some privacy matters.

13 Learning points, recommendations, limitations and conclusion

This final chapter discusses and integrates the research findings to spell out recommendations. In addition, it highlights the limitations of this study and suggests avenues for further research into the topic before concluding the thesis.

13.1 Learning points and recommendations

Several learning points for the debate on human rights for older people in care homes can be deduced from this thesis. These translate into recommendations for those who are involved in the international and national debates on the rights of older people and for those who wish to integrate human rights into the care home community.

Chapter 2 set out the human-rights-related international and national context in which this research took place. In the context of the processes discussed, older people in care homes are generally considered to be equal rightsholders; governments, care home providers and staff are responsible for providing high-quality care services that do not violate human rights. However, from this research on human rights in English care homes emerged multi-layered, contextual complexities around applying an international equal human rights rhetoric to care homes for older people. As argued in Chapter 4, the continued reliance on the UK government as the duty-bearer of human rights on one side, and the regulation of a largely independent care home market on the other, has produced a fragmented and unequal human rights framework for care homes in England. This is accompanied by uncertainty about its practical value for people living in them. Although the CQC's human rights approach is a factor in the human rights framework, it does not bridge the gap in legal protection between publicly funded and self-funded individuals. Furthermore, the future of the CQC's human rights approach depends on the sustainability of its organisational mindset and current priorities.

Chapter 3 explained that the health needs of the care home population are increasing. It also described the challenges faced by care homes that rely on public funding and by care workers, care home managers and relatives. If human rights are to have an impact on the lives and work of people living in, working in and visiting care homes, they must take effect in the light of such contextual considerations.

In addition, this thesis proposed a typology of perspectives on the potential role of human rights. Several approaches to the topic emerged, some of which understand human rights merely as a tool (legal, normative or both) for pursuing a particular agenda, and others which consider the protection of human rights to be the goal in itself. Furthermore, each perspective saw potential stumbling

blocks in making the potential role of human rights a reality. This again highlights the complexity of applying an equal human rights rhetoric to England's care homes and their residents.

Taking this into consideration, this thesis recommends that contributors to debates on older people's human rights specify a purpose and rationale for the debate beyond the common narrative of wishing to combat ageism and achieve "active ageing". This may help navigate the contextual complexities and realities of care home communities. A purpose and rationale could be based on social justice (e.g. Harding, 2018), perhaps combined with theories of ageing, in order to clearly determine and provide an actionable direction for responsibilities and duty-bearing agents.

This study also suggested that the topic of human rights is subjectively constructed and can be emotive for people in the care home community. The interview findings show that each participant in each group approached the topic from their point of view, as could be expected. However, they also show that this point of view can be heavily influenced by personal histories (for example, professional backgrounds and issues of self-identity, including perceptions of one's role in the care home system) and by the quality of relationships with family members and co-workers. The concept of human rights can trigger complex associations between such personal points and wider perceptions of human rights in general, care homes and people in society (including older people, care workers and people with a migrant background). Therefore, this thesis recommends that anyone who wants to integrate human rights more closely into a care home does *not* take for granted a shared understanding of the concept of human rights and is aware of the subjectivity and potential emotionality of the topic.

The study also suggested that considering specific rights (such as the right to privacy) in conjunction with concepts (such as fairness, respect, dignity and autonomy) can draw out a framework for human interactions and structural and environmental pre-conditions that respect those rights in an institutional, communal context such as care homes. Therefore, care homes that want to integrate human rights into their organisational ethos may benefit from exploring the topic with residents, staff and visitors using a mix of value-based communication and specific rights.

13.2 Limitations

The limitations to this research are inherent in either human rights research or the study design. There is no single agreed definition of human rights or its foundations (Landman, 2006). Indeed, human rights are contested and even rejected altogether by some (e.g. Hopgood, 2013; Posner, 2014). As such, examples of human rights enquiry face criticism from individuals who have competing understandings of human rights. This thesis adopted a "universal declaration model of

human rights", which took the international human rights framework as a starting point for the research. This is common practice amongst human rights researchers (Andreassen et al., 2017 p. 4). It provided a clear definition, which was useful for spelling out and identifying the starting premises for and assumptions about human rights. However, it also makes the thesis vulnerable to criticism from people with opposing views on the definition of human rights.

Human rights researchers are sometimes accused of not being critical enough, accepting the underlying premises and assumptions or violations in order to pursue a human rights agenda (Andreassen et al., 2017 p. 5). To tackle the potential criticism of bias, care was taken to be as objective as possible in the research process and whilst analysing and interpreting the findings to answer the research questions. This has come at the expense of some relevant topics that could have been discussed in more detail. For example, the perspectives tended to be resident-centric, only occasionally considering the human rights of other people in the care home community. The rights of family members were not mentioned at all.

From a theoretical and conceptual perspective, the thesis is limited in its engagement with relevant thought processes, including gerontological theories of ageing and theories of social justice and human rights. The intention was to provide as neutral a basis as possible for capturing people's perspectives, rather than superimposing the researcher's views and pre-chosen theoretical frameworks. However, it emerged from the findings that such engagement could help to further the international and national debate on the human rights of older people in general and those living in care homes specifically.

From a methodological point of view, given that any human rights research should aim to be as inclusive as possible, this research is limited by the lack of diversity in the participant cohort. The participating care homes were located in affluent areas of the south of England. All the care home managers, residents and their relatives had a white British background (see Chapter 5). Only two people with a BAME background and one person chose to say that they had an LGBTQ+ background were interviewed. For people with more diverse backgrounds, experiences of living in, working in or visiting a care home may present distinct challenges with regard to human rights (e.g. Hafford-Letchfield et al., 2018). This thesis touched on some potentially relevant points but did not engage with them in any depth.

Excluding people who lacked the capacity to consent to participate in the research is another limitation. A large part of the care home community consists of people with cognitive impairments, and these individuals have also been excluded from previous research (Alzheimer's Disease International, 2013; Davies et al., 2014). The reason for this exclusion is discussed in Chapter 5. Due

to the general approach of this research on human rights in care homes for older people, the findings are often irrelevant to people who have a significant cognitive or physical impairment or who are at the end of their life. Although this research pointed out several complexities in human rights and social care provision for people with dementia, other cognitive impairments or physical impairments, it did not go into any depth. This includes the research on the right to privacy, which did not tackle in depth the potential issues involved in protecting the privacy of people with cognitive impairments.

Some groups who are relevant to care home systems were missed out completely. They include healthcare professionals (such as GPs and nurses who come to the care home), volunteers and activity co-ordinators, and owners and providers of care home groups. Their voices could have added substance to the perspectives – and, of course, these people are part of the care home community.

A further limitation relates to the quantitative elements of this study, which produced merely indicative material. Although this study can add to knowledge about good privacy practice in care homes, further research is necessary to confirm that the model developed in this thesis can indeed add to the evidence base.

In addition, this human rights study focused on socio-empirical rather than legal research. The reason for not engaging in more extensive legal analysis was given in Chapter 5. Nevertheless, some degree of legal analysis was necessary to draw out relevant contextual points. The researcher has a background in law (LLB (Hons.)), which was useful in this respect. Care was taken to mention that the analysis of human rights law and other relevant laws reflects the opinion of the researcher, but such analysis may lack methodological rigour. The thesis also lacks in-depth engagement with potentially relevant case law and legal experts, who might have provided an enhanced perspective on the researcher's interpretation of the legal framework for human rights in care homes and the law-oriented perspectives.

Finally, the findings on the CQC's perspective reflect the author's interpretation of the data and the interviews with CQC experts in their own capacity. They may not represent the CQC's official stance on the topic of human rights. To make these findings reliable, it would be necessary to engage further with the CQC to verify the interpretation of the findings.

13.3 Suggestions for further research

In many ways, this study raises more questions than it answers. Every perspective uncovered potential areas for further research, some of which have been mentioned in Chapter 10. This section suggests the most pressing areas for research in the light of the findings.

Firstly, the findings of this study could be taken further. As explained in Section 13.2, this research is not representative due to the demographics of the sample. Further research could consider perspectives from a more diverse sample of people in care homes across England or could take a more specialised angle, focusing perhaps on people with a BAME background or people with dementia and other types of cognitive and non-cognitive impairment.

The right to privacy in care homes model is a product of this thesis. It would need to be verified and tested in a more targeted piece of research. Technologies, such as CCTV cameras, would need to be considered.

Secondly, taking account of the discussions of this thesis (especially in Chapter 4), it is pressing to conduct socio-legal research that considers the value of Section 73 of the Care Act 2014 regarding access to legal recourse in the context of care homes. This could include legal analysis, an exploration of how law is used in care homes, or an exploration of the experiences of people who decide to access the justice system. It could extend to research questions that consider if and how care home residents and their families can and do access information about human rights, social workers, advocacy services and legal aid, as well as the barriers to this.

Thirdly, in this thesis human rights were understood as a relational concept. The research findings suggested that human rights can shape relationships but are also dependent on them. This includes the relationships between care workers and residents, between residents, between care workers and relatives, between residents and relatives, and so on. Conducting human rights research in combination with psychological and organisational development theories could provide insights into how and whether human rights should be integrated more closely into practice: in an organisation and in the wider system. Such research could also consider power discourses and the intersectionality of ageism and other forms of discrimination in order to explore how “human rights violations” unfold through interactions between people in the care home community, and how those violations could be prevented.

13.4 Conclusion

This qualitative study had three broad aims:

1. To contribute to the debate on the rights of older people in long-term care by exploring multiple perspectives on the potential role of human rights in the context of care homes.
2. To build a mutual understanding of good practice in respecting care home residents' right to privacy.
3. To contribute to human rights research involving care home residents, care home managers, care workers, relatives of residents, and the CQC as the regulator of care services in England.

A typology of perspectives and a right to privacy in care homes model were developed. These were based on interviews with people working in, living in and visiting care homes and on data collected from the CQC. The data showed that people in care homes and the CQC experts hold a wide range of perspectives on the topic: a common understanding cannot be taken for granted. The study on the right to privacy – together with the typology of perspectives – proposed that this right could play a multi-dimensional role in care homes.

The contextual chapters presented the international and national context in which this study took place. It was argued that whilst traditional conceptions of international human rights consider governments as the main duty-bearers, a trickling-down process is transferring these duties to non-state actors. This opens up a discussion about the human rights obligations of private care home providers. Furthermore, the international debate on human rights and older people highlights the equal rights of older people, including care home residents with and without physical or cognitive impairments. In this debate, care homes are often considered potentially risky places for human rights, in which older people experience possible violations of these rights (such as ageism, abuse and neglect). In England, it was argued, there are signs that such a trickling-down process is taking place. Many private care home providers are now directly accountable under national human rights legislation and a regulatory care home inspection mechanism that is based on human rights. Furthermore, in England perceptions of care homes are widely negative. They are seen as having the inherent potential to harm older people, and community care is preferred over institutionalised care. Given these contextual points, the topic of human rights in English care homes, and their practical meaning for those who live in, work in and visit them, is a significant one to study.

Chapters 2, 3 and 4 further highlighted some contextual issues to be aware of when conducting human rights research in care homes. The human rights framework governing English care homes is complex and creates division between different groups of residents. This is due to the continued

reliance on governments and public authorities as the main duty-bearers of human rights, an argument that was supported by the CQC documents analysed for this thesis. Furthermore, the concept of human rights is perceived negatively in some parts of the population. Older people also experience ageism in English society. In addition, care homes were outlined as complex systems of relationships between various actors: residents, staff, visitors, regulators and commissioners. Many of the contextual "complications" became apparent in the findings and discussion of this thesis.

It emerged from the study that there are multiple approaches and perspectives on the potential role of human rights in care homes for older people. The different approaches and perspectives brought forward many considerations about how to realise – and even whether to realise – this potential role of human rights. Importantly, analysing the typology and privacy model together offered an alternative way to view care homes in society. Care homes can be re-envisioned as potentially rights-enabling new homes for older people, in which they are seen as rightsholders and in which human rights can frame relationship boundaries. However, some perspectives critically engaged with the concept of human rights, questioning its purpose as a normative and legal concept. The challenges of putting human rights into practice were discussed; these were found to be especially applicable in places of communal living and in caring for people with cognitive and physical impairments. Ultimately, for human rights to have any purpose in care homes, the study suggests that the concept, with its normative and legal force, must be understood and applied with a sensitivity to the varied experiences, identities and realities of residents, staff and visitors, taking into consideration the wider national contexts in which care homes exist.

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List of appendices

Appendix 1: The right to privacy literature review

Respecting care home residents' right to privacy: what is the evidence of good practice?

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Abstract

Purpose – *The purpose of this paper is to review and discuss evidence of good practice in respecting care home residents' right to privacy. The right to privacy is a fundamental human right as enshrined in international and domestic law and standards. In the context of increasing interest in using a human rights approach to social care in care homes for older people, this literature review summarises research evidence on what respecting the human right to privacy of care home residents entails in practice.*

Design/methodology/approach – *This literature review followed a rigorous systematic approach to the scoping review, inspired by the Joanna Biggs Institute's guidelines for conducting systematic reviews. A total of 12 articles were included in the review.*

Findings – *The research took a multidimensional understanding of privacy in their studies. The dimensions can be categorised as physical, inter-relational or related to personal data. The review highlights three good practice points. First, it is good privacy practice in care homes to make available single-occupancy bedrooms to residents since this offers the opportunity to personalising this physical space with furniture and other belongings, adding a sense of ownership over the space. Second, residents appreciate being able to choose when and how they spend their time in their own bedrooms. Third, it is good practice to respect residents' private physical space and private choices, for example by knocking on doors before entering or agreeing with the resident when it is permissible to enter. The review also found that in some studies privacy considerations were relevant to communal living areas within care homes, including the use of surveillance cameras and the sharing of personal data.*

Originality/value – *This literature review adds to the body of academic literature on human rights and social care in practice. It also highlights areas for future research relating to the right to privacy in care homes.*

Keywords *Older people, Human rights, Care homes, Good practice, Right to privacy*

Paper type *General review*

Background

The right to privacy is a fundamental human right, contained in Article 12 of the Universal Declaration of Human Rights and Article 8 of the European Convention on Human Rights 1950. This states that "Everyone has the right to respect for his private and family life, his home and his correspondence".

Academic and non-academic authors have recognised the importance of maintaining the human right to privacy of care home residents as part of a dignified and autonomous life (see Cahill, 2018; Care Quality Commission (CQC), 2017; Bayer *et al.*, 2005). A wider debate on a human rights approach to social care in residential care homes is gaining momentum and with it the right to privacy of care home residents (e.g. Cahill, 2018; CQC, 2017).

This review of research aims to report evidence of good practice when care home residents' privacy is respected. Thus, it systematically focusses on reporting evidence of practice in care homes which enables residents to have a sense of privacy. Whereas some research on the right to privacy and relevant practice has taken place in acute hospital settings (e.g. Baillie, 2009; Leino-Kilpi *et al.*, 2001), less addresses the context of care homes and social care.

Privacy as a concept is notoriously hard to define, as noted widely in the literature (Tugendhat, 2017, p. 132; Westin, 1967; Bauer, 1994). Rather, it is considered multidimensional, with no one universal definition. As a human right, it is an essential aspect of human dignity. The state must respect, protect and implement the right to privacy and courts of law have applied the right to privacy in a large variety of different cases (Tugendhat, 2017). Scott and her colleagues argue that the concept is relevant to all areas of human activity within society (Scott *et al.*, 2003a, b). However, everyone's privacy needs are personal to them and therefore it is contended that they cannot be generically defined (Scott *et al.*, 2003a; Burden, 1998).

The protection of privacy is core to ethical nursing practice (Nursing and Midwifery Council (NMC), of Ethics, 2008; International Council of Nurses, 2012) and some research has explored what the concept means for hospital settings (Leino-Kilpi *et al.*, 2003; Schopp *et al.*, 2003). To define good nursing practice, authors have attempted to define privacy for their purposes. Woogara (2005), for example, in an article on patients' right to privacy in hospitals used this definition:

> Privacy is broadly distinguishable as two forms: privacy of the person and information privacy, Information privacy implies that strangers should not obtain knowledge of patients' data without permission. Privacy of the person denotes a sense of identity, worth (dignity), autonomy and personal space that each adult human being has: a sense of boundary between "I", "me", "mine" and other people and the world (Woogara, 2005, p. 274).

This current review is not based on one definition. Rather definitions of privacy were extracted from the articles that were included in this study. The review shows that in care homes the concept of privacy is also multidimensional. Whereas there are factors that seem to make it easier for care home staff to respect residents' privacy, such as the availability of single-occupancy rooms, the evidence suggests that residents' ability to make choices, to be autonomous and communicate effectively with staff are pivotal in respecting their right to privacy.

Method

This review followed a systematic approach inspired by the Joanna Biggs Institute's (JBI) manual for conducting systematic reviews (JBI, 2018). However, due to the limitations further outlined below, this review is essentially a scoping review based on a systematic approach.

According to the JBI, systematic reviews aim to provide a comprehensive, unbiased synthesis of many relevant studies in a single document using rigorous and transparent methods. The attempt is to uncover "all" of the evidence relevant to a question (JBI, 2018). JBI's approach was considered most relevant for the purposes of this review, as it is particularly suitable for the research question and the nature of the body of literature, which is mostly qualitative rather than quantitative. Other methods, such as the Campbell systematic review process (Campbell Collaboration, 2017) were considered but not found suitable either because of the methodologies or the kind of evidence necessary to conduct such reviews.

The possibility for bias and errors should be kept as limited as possible to ensure the quality in systematic reviews, according to the JBI. As such, a step-by-step process should be followed. The steps are:

1. formulating a review question;
2. defining inclusion and exclusion criteria;
3. locating studies through searching;
4. selecting studies for inclusion;
5. assessing the quality of studies;
6. extracting data;
7. analysing and synthesising the relevant studies; and
8. presenting and interpreting the results.

Search strategy

RQ1. What is the evidence of good practice for respecting care home residents' right to privacy?

The research question was developed in January 2018 by the authors and noted down in a research protocol, together with the search strategy, the inclusion/exclusion criteria and the data extraction tool.

A systematic literature search took place in January and February 2018. Five databases (CINHAL, Web of Science, ASSIA, PubMED and Jstor) and three journals (*Journal of Elder Abuse and Neglect*, *Ageing and Society* and *The Journal of Adult Protection*) were searched online using a combination of four keywords and their variants. The keywords were: "right to privacy", "privacy", "private life", "private space"; "care homes", "residential care", "nursing home", "long term care"; "older people", "elderly", "aged"; and "best practice", "good practice", "protection", "respect", "dignity", "quality of life". The articles that were identified were furthermore scanned for additional articles. In this initial step, 149 articles were identified, of which 15 were duplicates. The remaining records were screened against the inclusion and exclusion criteria set out below. The authors reviewed potential articles in February 2018. The inclusion and exclusion criteria were as following:

Inclusion criteria

1. privacy or one of the variables included in the title, abstract or the keywords;
2. peer reviewed articles written in the English language and published between January 2000 and January 2018;
3. research context of nursing/care homes or other long-term care facilities for older people providing social care;
4. included evidence related to good practice regarding residents' privacy within the care setting; and
5. qualitative, quantitative, mixed method papers and literature reviews were included.

Exclusion criteria

1. Studies not written in English.
2. Research setting of health/acute/short-term care e.g. hospitals or respite services and privacy in health/nursing care.
3. Research focussing on groups other than older people; such as children, young people or pregnant women/mothers of new-born babies.
4. Aimed at identifying bad but not good practice or offering "only" a theoretical discussion of privacy.

In total, 21 full-text articles were assessed for eligibility of which nine were excluded based on the inclusion/exclusion criteria, using the PRISMA Flowchart (PRISMA, 2009) as recommended by the JBI (JBI, 2018). The remaining 12 articles were tested against the JBI's critical appraisal tool for qualitative research, systematic reviews and text and opinion (Joanna Briggs Institute, 2017a, b, c). The articles that were included provided evidence for good practice either through original research or through rigorous methods used for reviewing literature. The main reason for exclusion was that the articles did not provide any evidence or expert opinion for good practice when respecting privacy in care homes or long-term care settings.

Data extraction and analysis

Data were extracted from each of the 12 articles retrieved according to a predefined template (Table I). The template recorded basic information about the study, such as title, research aim, context and method, as well as the definition of privacy used in each study, the main findings, and reporting of evidence for good practice. A thematic synthesis of the data was used to obtain the results of the review.

Table I Overview of articles and data extraction template

Title of study	*Publication*	*Author/Year of publication/study location*	*Study participants*	*Method*	*Definition of privacy in study context*	*Study aim and relevant findings*	*Good practice identified in text*
Sexual consent capacity: ethical issues and challenges in long-term care	*Clinical Gerontologist*	Jennifer Hillman/ 2016/USA	Care home resident, male, aged 75 years ($n=1$)	Qualitative case study	Author considers privacy in the context of expression of sexuality in care home residents. She suggests that privacy is a multi-dimensional right. Privacy is a physical space in order to engage in sexual activity and intimacy/Privacy as relational space between two or more people, in which they choose to engage in sexual activity. She also argues that this needs to be balanced with a consideration for potential harm to the resident and others' rights	Aim of the study was to find out whether sexual consent capacity assessment can support expression of sexuality in care homes Findings: Sexual consent capacity assessment can help to respect care home residents' expression of sexuality but also protect them from harm and the rights of others	Assessment of sexual consent capacity requires a careful evaluation of a resident's knowledge, reasoning and voluntariness that includes an awareness of ethical issues, family dynamics, environmental constraints, legal rights, staff attitudes and overarching stigma. The use of an interdisciplinary committee or team can provide essential information regarding underlying medical, social, familial, financial and religious issues that may contribute to an understanding of the resident's sexual behaviour
Autonomy, privacy and informed consent 3: elderly care perspective	*British Journal of Nursing*	Scott, P.A. *et al.*, 2003b/Scotland as part of a European study including Finland, Germany	Care home residents and nurses (n=261; residents n=101; nurses n=160)	Quantitative study (structured interviews for residents, self-completion questionnaire for staff)	No single universal definition, privacy is a multidimensional concept	Explored the ethical issues in maintaining privacy in long term care settings. In total 11, privacy items were explored. The authors found consistent agreement between staff and residents. The results indicate that nurses seem to be sensitive to protecting residents' privacy during nursing care activities	Authors argue that the positive responses in the study regarding privacy stem from good facilities, public engagement and education around the right to privacy
Surveillance technologies in care homes: Seven principles for their use	Working with older people	Fisk, 2015/UK		Theoretical paper with practice implications based on pre-existing evidence about care home residents' opinions on the use of surveillance cameras in the care home environment	No definition for privacy is forwarded. Author speaks of privacy in the light of autonomy, data protection, choice and consent to the transmission, sharing, erasure, processing and storage of video or image footage. The author recognises that the risk for privacy to be compromised is greatest when personal tasks are undertaken e.g. in the bath-and bedroom. He also recognises the need to balance autonomy and the duty of care	The author explores principles around the use of assistive technology, particularly telecare systems such as monitoring technologies including cameras, "hidden mirrors" (technology to view pallor, pulse and breathing rate) and audio recording devices in care homes in order to minimise negative impact on the right to privacy	Author forwards following principles for the use of assistive technology: Overt surveillance (i.e. visible cameras) inside care homes and transparency around it in the communication with residents, staff, contractors and relatives Due regard to residents' consent for cameras in private bedrooms and careful consideration of how the footage is processed and kept Safeguards in place regarding who can access information gathered through surveillance technology. Data, images or video footage should be treated as if they belonged to the residents Careful judgement on how technology can support a conflict between autonomy and duty of care

(continued)

Table I

Title of study	*Publication*	*Author/Year of publication/study location*	*Study participants*	*Method*	*Definition of privacy in study context*	*Study aim and relevant findings*	*Good practice identified in text*
	Ageing & Society,	Harnett and Jonson, 2017/ Sweden	Residents, relatives, staff and managers of 5 care homes (n=45 participants, 14 focus group interviews and 7 individual interviews)	Qualitative, observation and interviews, using Erving Goffman's frame analysis (Goffman, 1974)	Authors understand privacy as an essential part of a home-like atmosphere in a care home. Privacy means personal physical space as opposed to communal, public space, personal preference and choice as opposed to control through care home staff and managers. The authors refer to "private meal frames" as mealtime situations, in which residents have a control over what they eat, where they eat it and when they eat	The study has three findings: (a) an institutional frame for care home mealtimes was dominant (b) there were substantial difficulties in introducing private frames (c) successful creation of private or home like mealtimes illustrates an overlooked skill in care work. Creating a non-institutional mealtime depended on staff interaction with residents Study suggests that private framing of mealtimes is to be preferred over institutional framing. Private meal scripts are personal, residents have control over what they eat, when and where they eat. Private meal scripts challenge paternalistic and institutional scripts	Staff initiated discussion among residents using self-disclosing comments, personal anecdotes and the introduction of topics of common interest Such discussion involved staff acting outside institutional meal scripts and to some extent outside their expected work roles. The effect was the creation of what was both personal and private, which was clearly appreciated by residents and staff alike
The factors influencing the sense of home in nursing homes: a systematic review from the perspective of residents	*Journal of Aging Research*	Rijnaard *et al.*, 2016/ The Netherlands	Systematic review		The authors understood privacy as an essential contributor to a feeling of being at home. The authors suggest that privacy is a multidimensional concept that includes the physical space, a psychological space involving choice and control and an interactional space between residents and co-residents as well as staff	The review identified 15 "major" and "micro" factors under three themes influencing the sense of home of nursing home residents. The three themes are attitudes and social interaction, the built environment and the outdoor environment. The preservation of a sense of privacy is an essential part within various identified factors and include a private space	The authors identified following good practice: Physical private space: Having private spaces, with private sanitary facilities (toilets but not necessarily showers/bath tubs), ideally with various rooms including a separate bedroom or recess for sleeping, Residents are free to decorate and make the room familiar and personal with own furniture, memorabilia, pictures and paintings Psychological/interactional private space: Residents can withdraw from communal areas into their private space, in which they can spend time as they wish. Within this space, they can keep old habits such as performing household chores, being able to do things oneself, being able to care for oneself, Residents can invite and host guests in their private rooms, conversations in isolation from others are possible. Rooms can be locked. Agreement on the use of keys appears to be important in the relationship and respect of privacy between staff and resident. Although nursing staff have keys, the locked door symbolizes privacy. The staff are welcome when the residents need assistance Residents receive help mostly from a caregiver instead of technological solutions

(continued)

Table I

Title of study	*Publication*	*Author/Year of publication/study location*	*Study participants*	*Method*	*Definition of privacy in study context*	*Study aim and relevant findings*	*Good practice identified in text*
Maintaining dignity for residents of care homes: a qualitative study of the views of care home staff, community nurses, residents and their families	*Geriatric Nursing*	Hall *et al.*, 2014/ England	Care home managers, care assistants, care home nurses, community nurses, residents and their families (*n*=121, managers *n*=33 ,care staff *n*=47, residents *n*=16, relatives *n*=15 and community nurses *n*=10)	Qualitative, interviews	For the authors privacy is an aspect of respecting dignity. The author defined the concept as seclusion from the presence or view from others. The authors argue that privacy is related to choice, control and respect. They suggest that it is a multidimensional concept, including personal physical space, private data	69 out of 121 participants considered privacy to be an essential aspect of maintaining dignity in a care home setting. Perceptions of dignity must be balanced with considerations of risk, particularly for people with dementia	Respecting residents personal space, like knocking before entering a room, closing curtains and doors when providing personal care. Residents bodies are shielded from view of others. Having a private room respecting of information which means not discussing personal information or reading letters in front of others. Seeking permission to enter a room
The implementation of new generation care surveillance technologies	*Gerotechnology*	Van der Weegen, Lukkien and Cornelisse, 2016/ The Netherlands	Institutional psychogeriatric care and care for people with disabilities (ages unreported) (*n*=3 sites)	Focus groups (questionnaires) and interviews inside the 3 research sites	Authors do not define privacy in the article	Smarter algorithms in ambient intelligent surveillance technology can decrease the level of false alarms during the night, which leads to enhanced privacy, autonomy and comfort in residents and reduction in workload for night staff	Personalised surveillance technology with training, coaching and deployment of super users, individuals who can maintain the systems. Small scale pilots to map context specific needs and barriers prior to organisation wide implementation
The design of caring environments and the quality of life of older people	*Ageing & Society*	Barnes, 2002/UK	Literature review		Privacy in the physical environment: visual, acoustic and olfactory (Keen, 1989) need to be separate from others personal space, which is defensible to others and becomes claimed territory with control over it	Authors argue that privacy in care homes can help to increase or maintain the quality of life in care homes. Evidence from the reviewed literature suggests that personal, defensible space is a major factor for life satisfaction. The determinants of enhanced or maintained quality of life may broadly be summed up as those factors which permit residents to control and organise their life in care	Personal, private space and spaces for interaction. Personalise rooms. Decide on ventilation/temperature levels
Architectural factors influencing the sense of home in nursing homes: An operationalization for practice	*Frontiers of Architectural Research*	Eijkelenboom *et al.*, 2017/ The Netherlands/ International	Literature analysis		Authors define privacy in terms of "private space" opposed to public space i.e. a private room as opposed to a shared room. In this private space, a resident can be on his/her own, talk in private, and create a personalised environment, with personal belongings and furniture	The study aimed to examine the architectural factors that contribute to a sense of home and how these can be implemented in design guidelines for practice. The built environment can contribute to a sense of home in nursing homes, of which privacy is an essential part. The article provides evidence-based design guidelines for a care home environment	Authors identified following good practice: Residents have a private space, at least bedroom but ideally also sanitary facilities and space to host guests. Residents can control their privacy by withdrawing from public spaces and by locking the doors In their private space, residents have control. They can perform chores, talk in private or be on their own. The private space is personalised, with personal belongings and furniture and residents have control over these belongings Rules between resident and staff govern the private space e.g. the doors are not opened without prior notification e.g. through knocking

(continued)

Table I

Title of study	*Publication*	*Author/Year of publication/study location*	*Study participants*	*Method*	*Definition of privacy in study context*	*Study aim and relevant findings*	*Good practice identified in text*
Older people's experience of their free will in nursing homes	*Nursing Ethics*	Tuominen *et al.*, 2016/Finland	Care home residents (*n*=15)	Qualitative, interviews	The authors considered privacy in the light of "free will". The authors define free will as a feeling of being able to make choices freely and voluntarily among a range of possibilities according to personal values. In practice, free will means freedom from obstacles to carry out one's desires and a right to determine one's interest, values and life free of interference (Tuominen *et al.*, 2016, p. 23)	The study's purpose was to consider how older care home residents define free will and what factors promote or are barriers to expressing such free will in a care home environment. Older people experience own free will as an action consistent with their own mind. Major promoter of free will were good physical conditions and health, which impacted the ability to demand rights, when nurses were professionally skilled and respected them and their needs are understood	Authors identified following good practice examples: Having a private, single occupancy room. Residents can choose to Spend time in their own room or shared parlour
What evidence is there about specific environmental needs of older people who are near the end of life and are cared for in hospices or similar institutions? A literature review	*Palliative Medicine*	Rigby *et al.*, 2010/ UK based study, international papers in English language	Narrative review based on 29 papers		Authors speak of privacy in context of a private physical space, i.e. single bed rooms and spaces for grieving family members and in context of social interaction, i.e. being without the interference of others without choice, being alone	The environmental space for older people nearing the end of life or dying should support the individual's specific needs for social interaction and privacy, be homely, allow space for spirituality and support the caring activities of staff, families and residents	The authors do not directly comment on evidence for good practice in meeting the needs for privacy. But, in their discussion they mention good practice in terms of physical space and social interaction. As such, a mixture of single or multiple occupant rooms should be available, and individuals should be able to choose according to personal preference. Garden spaces should be accessible without requiring assistance by staff. Individuals should be given the choice to worship in their rooms, alone or with others
An exploratory study of Chinese older people's perceptions of privacy in residential care homes	*Journal of Advanced Nursing*	Pau Le Low *et al.*, 2007/China	Care home residents (*n*=20)	Qualitative interviews	According to the authors, privacy is a fundamental principle of humanity. They understand privacy as multidimensional with four aspects, as forwarded by Leino-Kilpi *et al.* (2001): physical privacy, psychological privacy, social privacy and informational privacy	Socio-cultural influences determine older people's perceptions of care in residential care homes. Participants shared their understanding of the meaning of privacy. One said that privacy is about concealing things from others, keeping secrets. Generally, the article suggests that residents consider privacy to be related to individual needs as opposed to the collective unity of the care home community. Many of the studies participants did not perceive privacy according to their interpretation of the concept relevant in a care home. Chinese values of maintaining balance and harmony shaped their perceptions of privacy and infringements of privacy. Chinese people valued psychological and social privacy more over physical and informational privacy. Development of culturally appropriate care is essential for respecting privacy	Authors argue for following good practice points: Increased sensitivity towards older people's interpretations of privacy by eliciting privacy preferences Availability of lockable cupboards to secure personal belongings, locking doors and closing curtains during bathing and toileting Covering up body parts during intimate care, care staff enter bathrooms with permission Being able to choose to spend time in isolation from others and when to talk to others. Being able to choose when to spend time alone with families by leaving the premises or retreating to personal bedrooms Family issues and household matters are not discussed in front of other residents

Limitations

This review had several limitations, which means that it does not qualify as a "systematic review" under the JBI's definition. For example, this review is part of a doctoral study with a single reviewer rather than multiple reviewers as necessary for a JBI review. The JBI software for conducting systematic review was not used and some of the steps involved in the process, particularly the double processing through a second reviewer, were not followed.

A further limitation to this review is that it does not represent all the literature available on this topic. For example, only peer-reviewed academic articles were considered. This means that potentially valuable literature, such as books and book chapters or contributions published by non-academic sources, do not directly inform this review (such items include, e.g. Cahill, 2018; Chadwick and Gallagher, 2016; Care Quality Commission, 2014).

The search terms used for this review presented another limitation. Only contributions with the word "privacy" and "care homes" or one of the variables in the title, abstract or keywords were included for initial review. It is possible that some authors have provided good privacy practice illustrations in articles which focus on topics other than privacy such as quality of life, respect or dignity in care homes.

As such, it is possible that this review has missed evidence of such examples because these authors did not mention privacy and/or care homes in the title, abstract or keywords of their contribution. However, due to constraints on time and resources, this review had to be limited to academic articles focussing on evidence for good privacy practice in social care within care homes for older people based on the keywords.

Results

Conceptualising privacy

The concept of privacy, as mentioned above, does not have one fixed definition. Thus it was not surprising to find a variety of approaches to the concept within the 12 articles. Essentially, many suggested that privacy of care home residents amounts to having control and choice over one's personal and exclusive space, including the body, personal belongings, bed and bathrooms, personal data, food, as well as time and relationships.

Some authors aimed to locate privacy within a wider philosophical idea, specifically the concepts of humanity (Pau Le Low *et al.*, 2007), dignity (Hall *et al.*, 2014), free will (Tuominen *et al.*, 2016) or homeliness (Rijnaard *et al.*, 2016). Here, authors considered privacy as an aspect of each of these concepts but without offering any deeper theoretical discussions of the relationship.

Few proposed a limited definition for privacy, such as "seclusion from view" (Hall *et al.*, 2014) or "personal defensible space" (Barnes, 2002). In one contribution, the authors argued that the concept is culturally sensitive and that everyone has his or her own understanding of it (Pau Le Low *et al.*, 2007).

Most commonly however, authors showed an extensive and multidimensional understanding of privacy. There was frequent reference to the "private physical environment or space" and "the private social/psychological/interactional space", which were considered as interrelated (Hillman, 2016; Pau Le Low *et al.*, 2007; Rijnaard *et al.*, 2016; Hall *et al.*, 2014; Eijkelenboom *et al.*, 2017). These private spaces were virtually always conceived of as opposite to public, communal spaces within care homes. Few mentioned "data privacy" as another dimension (Hall *et al.*, 2014; Pau Le Low *et al.*, 2007). Most papers discussed these dimensions in the light of the concepts of "choice", "control", "autonomy", "personal preference", "ownership" and "respect" (Fisk, 2015; Hillman, 2016; Pau Le Low *et al.*, 2007; Rijnaard *et al.*, 2016; Hall *et al.*, 2014; Eijkelenboom *et al.*, 2017; Van der Weegen *et al.*, 2016; Barnes, 2002; Tuominen *et al.*, 2016).

Some authors recognised that, in a residential care setting, at times the right to privacy must be balanced with other considerations, notably risk of possible harm to the resident in question and/or other residents (Hillman, 2016; Hall *et al.*, 2014).

The evidence of good practice from the articles can largely be organised under four themes: the ownership of private spaces, respecting private choices, protecting private data, and approaches to balancing the right to privacy and risks of harm. These are discussed in turn.

Theme 1: ownership of private physical spaces

The majority of researchers discussed the significance of private physical space in relation to care home residents' right to privacy (Hillman, 2016; Harnett and Jonson, 2017; Pau Le Low *et al.*, 2007; Rijnaard *et al.*, 2016; Hall *et al.*, 2014; Eijkelenboom *et al.*, 2017; Barnes, 2002; Tuominen *et al.*, 2016; Rigby *et al.*, 2010). The availability of private, single-occupancy bedrooms was frequently argued to be pre-conditional for ensuring privacy in any institutional care setting (Tuominen *et al.*, 2016; Rigby *et al.*, 2010; Eijkelenboom *et al.*, 2017; Barnes, 2002; Rijnaard *et al.*, 2016). Care home residents generally expressed a desire to have their own toilets for their own personal use and a separate exclusive room in addition to their bedroom. This would be for entertaining family and guests (Rijnaard *et al.*, 2016). Exceptions to this were end of life care settings, in which some residents in one study preferred to share their bedroom with others (Rigby *et al.*, 2010).

Residents appreciated the opportunity to personalise their own rooms with pieces of furniture, pictures and other items, which added to a sense of personalisation and thus privacy (Hall *et al.*, 2014). Lockable doors and/or lockers for personal items as well as being able to control ventilation and heating added to a sense of control over the private space. During personal care assistance, blinds or curtains on windows provided enabled the shielding of residents from the sight of others, which again added to a sense of privacy being respected.

One study (Pau Le Low *et al.*, 2007) was based in a Chinese care home, in which multiple occupant rooms are common. Residents reported that having available a locker to safely store personal items was valuable in terms of privacy considerations.

Theme 2: respecting private choices and personal preferences and leaving residents in control

The inter-relational, social or psychological dimension of privacy was often explained as residents being able to make choices, express personal preferences and staying "in control". Several good practice examples were highlighted, which were directly linked to the first dimension, namely, private physical spaces. Several authors also discussed good privacy practice within communal living areas of the care home. These will now be outlined in turn.

Private choices in private places. According to many authors, simply occupying a private physical space does not amount to good privacy practice in care homes. Residents must also be able to make choices regarding the use of these private spaces on several levels and have these choices respected.

First, residents reported that being able to choose when to withdraw from communal living spaces in the care home and spend time in their private rooms adds to a sense of control. Second, residents appreciated the opportunity to choose how they spend their time within their own private spaces. One study mentioned the value of residents being able to engage in household chores and caring for themselves (Rijnaard *et al.*, 2016). Residents also appreciated being able to invite others into their rooms and to engage in conversations. Another study mentioned the importance of being able to pray and worship in one's own room (Rigby *et al.*, 2010).

Several authors highlighted the need to protect the private physical space. There were numerous references to the importance of knocking on a resident's door before entering, providing residents with a key to their bedroom door and agreeing on rules about when a staff member or visitor can unlock a resident's door.

Private choices in public places. Some studies mentioned good practice in respecting private choices in communal spaces, such as gardens, living or meeting rooms. One study used the concept of privacy in relation to mealtimes and reported a shift in social roles between staff and

residents when the latter were provided with a choice over what, when and where to eat at evening coffee time (Harnett and Jonson, 2017). While the element of privacy is hard to determine, the researchers thought that change in social roles meant that staff engaged differently with residents, sharing personal anecdotes and common interests, which both residents and staff appreciated.

Another study (Rigby *et al.*, 2010) reported how family members of care home residents who were dying liked to be able to withdraw into a "private" space within otherwise communal living areas, in which they could feel on their own for a while. Accessible outside spaces, which residents could enter without asking for support, were another good practice example, as reported by residents within this study although the element of privacy is not explicit.

Theme 3: keeping personal information private

A few studies discussed the handling of personal information, for example relating to a resident's family or health, from a privacy perspective (Fisk, 2015; Pau Le Low *et al.*, 2007; Hall *et al.*, 2014). In one study, residents expressed a wish not to have family matters discussed in front of other residents (Pau Le Low *et al.*, 2007). In another, residents said that "personal information" should not be discussed or letters read out in front of others (Hall *et al.*, 2014).

Theme 4: balancing the right to privacy with risk of harm

Care home residents are often frail, in need of support and/or have cognitive impairment (Fisk, 2015; Hillman, 2016). Some studies highlighted the risk of harm to care home residents if the level of respect for their physical privacy and private choices was maintained to the same extent as those of residents without substantial impairment (Hillman, 2016; Fisk, 2015).

One study (Hillman, 2016) considered capacity to consent to sexual activity in a care home for residents with dementia. Whereas maintaining sexual relationships is an important part of a person's private life, in the case of people with dementia, lacking the ability to consent to such activity, the risk of possible harm either to themselves or others needed to be balanced. The author considered privacy in terms of physical privacy to be intimate and in terms of relationships, in which individuals choose to become intimate. The study reported that staff could use a sexual consent capacity assessment tool, which helped both the care home staff and the resident to decide whether the desired sexual activity was risk-free for the individuals wanting to engage in intimacy.

Another study (Van der Weegen, 2016) focussed on the availability of technological solutions to increase the privacy of care home residents and at the same time reduce staff workload. Such technology, which entailed surveillance cameras, was particularly said to be useful when staff members were trained how to maintain the hard and software and when everyone involved received detailed information about its uses and the way it worked.

Fisk (2015) forwarded specific principles for the use of monitoring technology, which includes cameras but also other devices such as health monitoring tools. He argued that such technology can be helpful in care homes settings but that ethical issues around its use need consideration. Fisk recommended that it would be good practice for surveillance cameras and other devices that capture images or footage of residents and others in the environment to be visible and that there should be transparency and consent as far as possible.

Discussion

This review has highlighted the many aspects of the right to privacy relating to care home settings, be it in theory or in practice. Despite the elusiveness of the concept, many of the authors proposed a similar idea in defining privacy – and good privacy practice – within a care home.

Three main good practice points emerged from the review. First, it is good practice to offer private rooms to residents, which can be personalised with furniture and other belongings, enabling individuals to make their own choices over decoration. Second, residents appreciate being able to choose when and how they spend their time within these private physical spaces without

being disturbed. Third, it is good practice to respect residents' private physical space and private choices by knocking on doors or agreeing with the occupant when it is permissible to enter. The review further highlighted that there are privacy considerations in communal living areas within the care homes, particularly relating to mealtimes. In terms of the use of cameras in care homes, consent and transparency around the use of such technology need attention to help balance the inherent risk of such devices in reducing residents' privacy.

Besides these good practice points, this review highlights the significance of skilled staff who elucidate and understand the needs of individual residents and who are willing to respect them. Privacy, as this review shows, is a person-centric concept, which in its very core is about individuals' lives in a community. Staff willingness to get to know the residents as individuals and engage with them seem to be a cornerstone for good privacy practice in care homes.

This review has also highlighted the need to balance the right to privacy with other considerations, particularly the duty of care and rights of other residents. This becomes especially relevant when a resident or residents have cognitive impairments and their decision making or insight is impaired.

Conclusion

This review shows that researchers conceptualise the right to privacy as a multidimensional concept in a care home, which demands certain environmental and inter-relational pre-conditions. The review also highlights the many aspects of the right to privacy that need to be considered in the light of duty of care and other rights. These aspects include the handling of personal data, the use of surveillance technology, sexual relationships in the care home, and so forth.

While this review provides a broad summary of good practice for respecting care home residents' right to privacy, it also highlights the need for further research and investigation of good practice. A range of systematic reviews could be useful, especially if they include all the relevant literature. In the light of a growing population of people with dementia, guidance on good privacy practice for people with dementia could be particularly timely and useful.

The literature search for this review also made apparent a lack of evidence-focussed contributions on the human right to privacy in care homes. In most of the articles included in this review, "evidence for good privacy practice" had to be extracted from a much broader focus on other related issues, such as sexuality, end of life or autonomy in care homes. No quantitative studies or targeted qualitative studies focussing on evidence for good privacy practice could be found. Some of the authors included in this review made the point that different people have different privacy needs. More in-depth research is needed to identify privacy needs of people living in care homes, including their wishes around the use of personal data and surveillance.

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Further reading

Emmer De Albuquerque Green, C. (2017), "Exploring care home providers' public commitments to human rights in light of the United Nations guiding principles on business and human rights", *The Journal of Adult Protection*, Vol. 19 No. 6, pp. 357-67.

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Appendix 2: Article published in The Journal of Adult Protection (Highly Commended in the 2018 Emerald Literati Awards)

Exploring care home providers' public commitments to human rights in light of the United Nations Guiding Principles on Business and Human Rights

Caroline Emmer De Albuquerque Green

Abstract

Purpose – *The purpose of this paper is to explore care home providers' public communications covering their commitments to respecting residents' the human rights. The discussion considers the United Nations guiding principles on business and human rights United Nations Guiding Principles on Business and Human Rights (UNGPs) and a domestic legal and regulatory human rights framework.*

Design/methodology/approach – *Qualitative content analysis undertaken in 2017 of 70 websites of England's largest commercial care home providers.*

Findings – *There are strong value-based public commitments in the websites of many English care home providers, which may or may not be interpreted as expressing their commitments to human rights.*

Research limitations/implications – *Research was limited to websites, which are public facing and marketing tools of care home providers. This does not provide inferences regarding the practical implementation of value-based statements or human-rights-based procedures or policies. This paper does not make any value judgements regarding either the public communications of care home providers or normative claims regarding human rights and care home service provision.*

Practical implications – *There is a need for clarification and debate about the potential role and added value of the corporate responsibility to respect human rights and the UNGPs' operating principles within the English residential care sector. Further exploration of the relationship between personalisation/ person-centred care and human rights might be useful.*

Originality/value – *This paper introduces the UNGPs and corporate responsibility to respect human rights to the debate on human rights, personalised/person-centred care, safeguarding and care homes in England. It adds a new perspective to discussions of the human rights obligations of care home providers.*

Keywords *Human rights, Safeguarding, Older people, Care homes, Public communication, United Nations guiding principles on business and human rights*

Paper type *Research paper*

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Introduction

Commercial corporations or not-for-profit organisations own and operate most English care homes (Laing, 2016). A "care home" is a setting in which individuals in need of care and support live on a long-term basis and receive emotional and social support as well as support with activities of daily living (Burstow, 2014). In some care homes in England, qualified nurses help other staff to provide 24-hour onsite healthcare. In England, private businesses, including care home providers, have a corporate responsibility to respect human rights of any individual who may be adversely affected by their services under the United Nations Guiding Principles on Business and Human Rights (UNGPs). Westminster government, under the same principles, has a duty to protect individuals from human rights abuses through the activities of businesses. To meet the corporate responsibility to respect human rights, businesses should engage in a

Received 26 September 2017
Revised 4 October 2017
10 October 2017
Accepted 10 October 2017

There are no conflicting interests in the research. The author would like to acknowledge Professor Jill Manthorpe and Dr Martin Stevens from the Social Care Workforce Research Unit at King's College London, who have provided invaluable feedback and support in editing the paper.

structured process of integrating human rights into their activities, including publicly and expressly committing themselves to human rights (UNGPs, PPc 13).

This paper reports the findings of a qualitative content analysis of 71 websites of large commercial care home providers in England that investigated if they made any public commitment to international human rights. It forms part of the author's PhD study on the "human rights approach" to social care in English care homes. This research took place within a broader consideration of the current domestic policy, regulatory and legal context in which English care home providers are operating. It shows that providers generally use value-based public communications, which may or may not be interpreted to be an express commitment to human rights. Practically, the study suggests the need for further clarification and debate regarding the potential role and added value of introducing the UNGPs to the English care home sector. It also suggests the need for further clarification regarding the relationship between the policy goal of personalised and person-centred care, safeguarding and human rights.

What follows is a definition of the concept of "human rights" and an introduction to the UNGPs. Next, the paper outlines the policy and legal human rights framework under which English care home providers operate. This includes a short discussion of policies on personalisation and person-centred care and their relationship to human rights. The paper then reports on the methodology and findings of the qualitative study of corporate websites, followed by a discussion and a conclusion.

Defining human rights

"Human rights" are deemed equal and inalienable entitlements, which are inherent in all human beings, irrespective of age, sex, ethnicity, disability and other personal characteristics (Ruggie, 2013). International and regional treaties and other sources of international law guarantee human rights legally and make up the modern, international human rights regime (Donnelly, 2013). This includes the Universal Declaration of Human Rights from 1948 – the cornerstone of the modern human rights regime – and regional instruments such as the European Convention on Human Rights (ECHR) from 1950.

Traditionally, the primary duty bearer for international human rights are states, which, under the international law, are obliged to respect, protect and implement human rights (Donnelly, 2013). This means they must not interfere or curtail human rights without a legitimate reason, they must protect individuals from any violations of their human rights and take action to ensure that individuals can enjoy their human rights (Office of the United Nations High Commissioner for Human Rights, 2014).

International and regional human rights law, including the ECHR, binds Westminster government too (Tugendhat, 2017). In 1998, the UK translated the ECHR into domestic law and adopted the Human Rights Act (HRA) 1998. The HRA requires public authorities and bodies carrying out a public function to protect and respect the human rights set out within the ECHR. Further, all laws passed by the parliament need to be compatible with human rights, and individuals can claim their human rights in British domestic courts.

The concept of human rights, including its definition, purpose and even legitimacy, has been subject to interdisciplinary debates (Andreassen *et al.*, 2017). It is not the purpose of this paper to make value judgements about human rights or the international human rights regime. Rather, it accepts the existence of the human rights regime without exploring its philosophical foundations or normative value.

The UNGPs

Endorsed in 2011 by the United Nations Human Rights Council after a six-year consultative process led by Professor John Ruggie, the UNGPs recognise and address the potential impact that businesses can have on individuals' human rights. Such impacts are visible within large-scale disasters such as the Samarco dam collapse in Brazil in 2015 or allegations of instances of forced labour and dangerous working conditions (Vogt, 2014). The UNGPs provide guidance to states and businesses about their responsibilities to prevent and address human rights abuses committed within business operations (UNGPs, general PPcs). The UNGPs have attracted various criticisms (e.g. Deva and Bilchitz, 2013). However, this paper does not engage with such criticisms but rather acknowledges the UNGPs' existence as a part of the international human rights regime.

The UNGPs rest on a "Protect, Respect and Remedy Framework". It says that states have the primary duty to protect individuals against human rights abuses by third parties, including those by businesses. For this purpose, they must implement domestic policies, legislation, regulation and enforcement mechanisms (UNGPs, PPc 1). Further, the UNGPs recognise the distinct responsibility of businesses to respect human rights (UNGPs, PPc 11). This corporate responsibility exists irrespective of whether a state is discharging its duty to protect (UNGPs, PPc 11). It requires businesses to avoid infringing human rights either directly or indirectly through their activities and to address any adverse impacts (UNGPs, PPc11). It also requires them to seek to prevent and mitigate adverse human rights impacts if these are directly linked to them by their business relationships (UNGPs, PPc11). Under the framework and the UNGPs, businesses are subject to relevant national human rights policies, laws and regulations as well as to what Ruggie calls a "widely recognized social norm" of a corporate responsibility to respect human rights (Ruggie, 2013). To clarify, this corporate responsibility to respect is not legally binding per se but businesses are bound by domestic law and regulation if their respective states are appropriately discharging their duty to protect (Nolan, 2014). Additionally, the UNGPs include a right to access effective remedy for individuals adversely impacted by business activities. Both states and businesses are responsible for putting in place such remedies (UNGPs, PPc 25).

The UNGPs include 31 "foundational" and "operational" principles to guide implementation. This paper considers mainly two of these. The first is Foundational Principle 1 of Part 1, requiring states to implement effective policies, legislation, regulation and adjudication. The second is Operational Principle 15a of Part 2, which explains that businesses should have a policy commitment in place appropriate to their size and circumstances to meet their responsibility to respect within their business activities. The matter of access to effective remedy is not considered in the present paper.

The next section of this paper establishes the relevance of UNGPs for English care home providers followed by a non-exhaustive outline of relevant English laws, regulations and policy, which hold providers accountable for human rights and will be referred to here as the "human rights framework". The paper does not engage in an assessment of the quality of such framework in the light of the UNGPs. These sections are followed by a report of the qualitative content analysis of care home providers' websites.

UNGPs' relevance to England's care homes

In 2013 and 2016, the Westminster government adopted national action plans on business and human rights, endorsing the UNGPs (Foreign & Commonwealth Office, 2016). The UNGPs apply across English businesses, disregarding size or sector (UNGPs PPc 14). However, for some sectors, the UNGPs are particularly relevant, especially if their activities pose significant potential for adverse human rights impact (UNGPs, PPc 14). As the English care home sector is largely commercial, most of it automatically falls under the remit of the UNGPs. Additionally, care home activities have potential for positive and negative human rights impacts, and thus the UNGPs could be relevant to the sector.

Care homes provide care and support to residents, most of whom are frail or have complex needs (Office for National Statistics, 2016). Furthermore, many residents are affected by dementia (Alzheimer's Society, 2014). They are thus vulnerable to physical and emotional abuse and other forms of violations of their human rights. Indeed, the United Nations has been concerned for a number of years with the protection of human rights of older care home residents and the issue features within the framework of an open-ended working group on ageing (Office of the High Commissioner for Human Rights, 2017) and consultations regarding the possible adoption of an international convention on the human rights of older persons (e.g. Hill, 2013). Some care homes in England have been subject to public scrutiny and sometimes legal action after alleged instances of physical abuse, neglect and other forms of "human rights abuse" of residents (Manthorpe *et al.*, 2016; Meenan *et al.*, 2015). This not only concerns England. Member organisations of the European Network of National Human Rights Institutions (ENNHRI, 2017) recently conducted research into the state of human rights protection and promotion in long-term

care for older people across six European countries. The resulting country reports highlighted that human rights concerns continue to exist in care homes across these countries but that there is also a wealth of good practices. Thus, care homes also have a positive impact on the protection and promotion of the human rights of thousands of people needing social care and support (ENNHRI, 2017; Burstow, 2014).

A "human rights framework" for English care homes

A supporting pillar for a human rights framework in England is the HRA 1998. Despite its restriction to public authorities and those organisations carrying out a public function, the HRA is directly relevant to many care home providers in England under Section 73 of the Care Act 2014.

The Care Act 2014 emerged from a policy process considering avenues to safeguard adults in need of care and support and ensure their wellbeing. Section 73 of the Act determines that care providers registered with the Care Quality Commission (CQC), the regulatory and inspecting body of care services in England, exercise a function of public nature and are thus bound by the HRA if care or support with this provider has been arranged by an authority and is paid for in whole or in part by it. Independent care home providers caring for publicly funded residents are thus accountable under the HRA. In 2015, approximately 53 per cent of older residents were publicly funded, according to England's means-based system (Department of Health UK Government, 2017). Care homes with exclusively self-funded residents are theoretically not accountable. Despite these limitations, the HRA raises the possibility of human rights litigation involving independent care home providers.

Under a regulatory dimension of the human rights framework, all CQC registered providers of care and support are subject to government regulation and, again, the HRA has been influential. The need for any public authority to act compatibly with human rights under the HRA has led to an increased interest in building "human rights-respecting" public services (British Institute of Human Rights, 2017). This includes the CQC (2014), a public authority, which adopted a "human rights approach to regulating and inspecting providers of care" (CQC, 2014). It aims to promote diversity, equality and human rights of care service users and members of staff in care homes, recognising that human rights apply to everyone within the care context (CQC, 2014, p. 7). Accordingly, the CQC integrates human rights and related principles within internal structures and activities as well as regulatory and assessment frameworks for care providers. For this purpose, it uses the "FREDA" framework of principles that are "fairness, respect, equality, dignity and autonomy". The CQC considers these principles to underpin human rights.

Under this approach, the role of care homes is "to promote" human rights of residents and staff through meeting CQC determined standards (CQC, 2014, pp. 20-1). The duty to ensure that human rights are protected, respected and fulfilled within care homes, thus stays with the CQC as a public body, and for care homes, it becomes an issue of compliance (CQC, 2014, pp. 20-1). In a recent report (CQC, 2017), the CQC recognises that integrating human rights and equality expressly into the provision of care can improve the quality of care.

Within a policy dimension of the framework, the concepts of "human rights" and the HRA have gained significance. This has taken place within related yet distinct policy moves to person-centred care and personalisation. Both concepts – personalisation and person-centred care – are rooted in a social movement for the empowerment and participation in decision making of people with physical and cognitive impairments and those who need care and support (Woolham *et al.*, 2015). Whereas the concept of personalisation often drives debates regarding personal budgets and consumer choice regarding care services, person-centred care mainly stands for maintaining identity and dignity through needs and preference-based assessments of care service provision (Leplege *et al.*, 2007). Both concepts feature in the legal and regulatory framework (e.g. Care Act 2014, Health and Social Care Act 2008 (Regulated Activities) Regulations 2014: Regulations 9) governing English care homes.

The link between personalisation, person-centred care and human rights is emerging. For example, Chetty *et al.* (2012) argue that the HRA provides a legal basis for personalised care with links between various articles of the ECHR and underlying principles of personalisation. Consequently, personalised care becomes an entitlement under human rights law (Chetty *et al.*, 2012). The British Institute of Human Rights argues that public services, which protect, respect and implement the

human rights of service users, should deliver high-quality person-centred care (British Institute of Human Rights, 2017, Elliott, 2017). In a recent publication of September 2017, the CQC refers to person-centred care as a "human rights approach to care" because it is based on respect and autonomy, which are both human rights related principles (CQC, 2017). However, within relevant domestic law and regulation, the link between human rights, person-centred care and personalisation often seems weakly defined, with Section 73 of the Care Act 2014 being only one of the few direct references to the HRA 1998.

The "human rights framework" introduced in this paper supports a largely legalistic and compliance-based understanding of human rights, based within the domestic human rights law.

The CQC's recent report recognises the existence of guidance for businesses (including care service providers) on human rights, without expressly mentioning the UNGPs (CQC, 2017, p. 17). The UNGPs rarely feature within the literature and the extent to which English care home providers are familiar with the social norm of a corporate responsibility to respect is unknown.

Research into public profiles – method, findings and discussion

Principle 15 of the UNGPs spells out operational principles for businesses to meet their corporate responsibility to respect human rights. According to the Principle's commentary, businesses should know and show that they respect human rights and should have certain policies and processes in place (UNGPs, Principle 15, commentary). The first step is to expressly and publicly state a commitment to meet the corporate responsibility to respect human rights (UNGPs, PPCs15 and 16). Thus, this research analysed online profiles of care home providers in England, aiming to report observations regarding the existence and content of such statements in the light of the UNGPs and the English "human rights framework".

Methods

Using principles of qualitative content analysis (Schreier, 2012), this research scanned and analysed websites and other publicly available sources (including investor and corporate social responsibility (CSR) reports) of 71 of the largest commercial care home providers in England. The sample derived from a prominent sector overview report from 2014 (Laing, 2014). Illustrative extracts have been anonymised.

Data collection followed a process of navigating public websites of the care providers, reading CSR or investor reports, and finally consulting some relevant external sources. Data were then extracted and analysed using the qualitative data analysis software MaxQDA. A dual coding matrix was produced, which was, on one hand, data driven and, on the other hand, based on searching the data for "prominent principles" extracted from England's human rights framework, the person-centred care and personalisation agenda and the UNGPs (see Table I).

Limitations. This research focussed on public statements and data sources, many of which are aimed at potential new residents and their families. No information regarding organisation internal policies and organisational value commitments or the status of implementation of whatever commitments care home providers made within their public profiles was gathered. As such, findings reflect the marketing strategy of care home providers. Findings do not suggest any knowledge about or assessment of internal management processes or mechanisms.

Data analysis is based on the researcher's own interpretation. However, a process of triangulation and validation of the findings with a range of sector experts was followed to aid reliability. The findings are not transferrable to other countries.

Findings. Care homes had adopted similar public profiles, with value-based frameworks, apparent consciousness of connected salient issues and a range of statements of commitments on how they achieve their values within the care home context. The data suggest that the person-centred care/personalisation agenda has had an impact on public profiles. Whereas some providers refer to the word "rights", they rarely use the concept of "human rights" within

Table I Outline of "prominent" principles of the human rights and the person-centred care agendas extracted from relevant law and regulation

"Prominent principles" UNGPs	*Human rights framework*	*Principles within person-centred care/personalisation agenda*
Corporate responsibility to respect human rights	Articles of the European Convention on Human Rights	Person-centred/personalisation/personalised care
Express reference to the word (international) "Human Rights"	Fairness	Informed consent
	Respect	Wellbeing (physical, emotional, mental health, social and economic)
	Equality	Dignity/respect
	Dignity	Independence
	Autonomy	Choice, involvement and control over day-to-day life
	FREDA principles	Meeting nutrition and hydration needs
		Participation/contribution to society/domestic, family and personal relationships
		Suitability of living environment, including privacy
		Protection from abuse and neglect

Sources: UNGPs, CQC (2014), Health And Social Care Act (England) 2008 (Regulated Activities) Regulation 9, Care Act (England) (2014)

public statements. As such, the statements may or may not be interpreted as public commitments to human rights. One provider made available the company's human rights, diversity and equality policy. No provider expressly stated a commitment to their corporate responsibility to respect human rights under the UNGPs.

Desired outcomes of life in a care home:

> Our Philosophy of Care recognises the importance of the individual: that each of our care facilities is the home of each resident and that we just work there. Our care planning is designed to deliver quality service and promote each resident's enjoyment of daily living.

Generally, care home providers expressed similar perceptions of what potential residents, their families and other consumers of their public profiles desire from life in a care home. The above quote was typical. Perceptions of desired outcomes include the provision of high standards of care, an enhanced quality of life for the residents and/or ensuring the wellbeing and happiness/enjoyment and flourishing of residents.

The public profiles also communicate strategies on how to achieve such outcomes. These strategies generally include a strong value framework, a focus on priority services and awareness of "salient issues", as follows:

Value-rich public profiles:

> We believe that every individual irrespective of their physical, social or psychological condition have the right to be treated with dignity and respect and to be supported to maintain choice and control over their own live. We work in a person-centred way to identify individual goals and ambitions, focusing on enablement and the promotion of personal dignity.

Virtually, all the public profiles are value rich, referring to various principles. These include preserving privacy, family and community connections. Some mention the principle of non-discrimination. Notably, one of the most common set of values referred to is the triangle of maintaining "independence, dignity and respect", as outlined in following quote:

> We strive to make life at (Company) care homes as stimulating and fulfilling as possible and are committed to ensuring independence, dignity and respect in every aspect of daily life.

The concept of dignity was often expressly defined by the providers and linked to the principle of respect, as in this example:

> Dignity in care[…]means the kind of care which supports and promotes, and does not undermine a person's self-respect regardless of any difference.

Further, there was generally a strong commitment to preserve the identity and individuality of residents by involving them and giving them choices in planning of their care and the structure of their days and thereby meeting their individual needs and preferences. This extract was typical:

> Soon after residents arrive we put together a personal care plan. By speaking to our residents, we are able to set out their needs and ask them about any personal preferences they might have, so we can tailor our care to their unique needs.

Table II once more summarises the most commonly referred to principles within the data, that is, those principles which the majority of the providers refer to on their webpages.

Priority services:

> We have no rivals when it comes to upholding family values and principles; Focus on treating all residents as individuals, with compassion and dignity, Encouraging an active social life within the home and the local community, Promoting a "dining experience" with award winning food and drink, where residents are in charge, Bespoke, tasteful furnishings and fittings, meticulously designed with residents in mind.

The large majority of care home providers on their public profile put emphasis on delivering three priority services. These are following:

1. To provide a sociable and active lifestyle for residents. The following statement is typical:

> The X Group of Care Homes strive to bring happiness to all of our Service Users who are in our care. We have our own programme of activities and entertainment.

Notably, many of the care home providers said they offer a large range of activities, tailored to the residents' preferences and interests. There was a notable emphasis on activities with local communities, for example, through shared activities with schools. Many homes expressly stated their intention to foster the integration of residents with local communities to counter social isolation:

2. To offer a homely and safe care home environment, as follows:

> Our homes are modern, spacious and provide a comfortable and safe environment for our residents to live in. All our homes offer a warm and friendly welcome.

Providers specialising in dementia care often highlighted the "safe" environment they offer. There further seemed to be a trend towards offering (or mentioning) amenities such as in-house hairdressers, cinemas and various outdoor spaces:

3. To make available nutritious and popular meals:

> We are here to make sure your new life is as comfortable and enjoyable as possible. We understand that good, freshly cooked food is vital to keeping healthy, as well as being one of life's great pleasures, so you can look forward to delicious meals created and cooked by superb chefs.

There seems to be broad awareness about the importance of individually prepared meals. A large proportion of the providers mentioned an in-house chef, who, they claimed, would be able to cater for individual preferences and needs.

Consciousness of salient issues:

> We understand that moving into a care home can be a difficult choice to make with the worry of losing one's independence and sense of control. We do everything we can to ease that worry for our residents and their families. From the moment a new guest steps through the door, we treat them with the love, respect and tenderness that we'd want for our own family[...].

In regard of desired outcomes and priority services together with the underpinning value frameworks, most of the care home providers publicly considered associated risks to achieving these. Many showed apparent awareness of a variety of salient issues by communicating them

Table II Commonly referred to principles on providers' webpages

Dignity	Choice	Independence
Respect	Privacy	Safety of residents
Family life	Individuality	Involvement

on their websites and addressed them openly. Table III below outlines some of these issues extracted from the data, together with providers' solutions:

Statements of commitment to person-centred/personalised care:

> Care is our business and our standard of care defines us as a company. Providing person centred care of a high standard is of paramount importance.

A majority of the public profiles included statements of commitment to person-centred or personalised care, as mentioned in the quote above. The concepts of person centredness and personalisation seemed to be used synonymously to represent care tailored to the needs and preferences of the resident.

Few direct commitments to "human rights" and none to the "responsibility to respect human right" were identified. But, occasionally, there was a reference to "rights" in one way or another within the value frameworks. This included references to the "right to dignity and respect" or "residents" "charters of rights". One home, for example, stated:

> We ensure that our clients' respect, dignity and right of choice are at the heart of everything we do.

A large proportion of the providers showed awareness of regulation and law and underlined its importance for their services, specifically for maintaining "high quality and standards of care". Again, no references to the HRA 1998, the UNGPs or the CQC's human rights approach were found.

Example policy statement on company's human rights policy:

> We encourage a working atmosphere, in which human rights considerations are carefully measured.

Notably, one of the sampled care home providers expressed its commitment to "human rights, diversity and equality" within an employee handbook, which is publicly available on the provider's website. The policy contained following characteristics:

- it expressly acknowledges the importance and interconnectedness of equal opportunities, diversity and "human rights" for the working atmosphere;
- it addresses members of staff, clearly outlining expectations and duties under the policy;
- it acknowledges human rights of residents as well as the human rights and correlative responsibilities of each member of staff;
- it identifies the human rights that are of most relevance for the care home environment including the right to respect for private and family life and freedom of thought, conscience and religion and freedom from discrimination;
- it highlights that staff receive relevant training, and the management team provides leadership on equality, diversity and human rights;
- it highlights that treatment of human rights, equality and diversity forms part of operational arrangements and needs to be balanced; and

Table III Overview of salient issues, exemplary risk factors and solutions mentioned on providers' webpages

Salient issue	*Exemplary risk factors*	*Exemplary solutions*
Privacy	Support with personal hygiene	Providing single-bedded rooms
	Entering personal space	Keeping doors to bathrooms shut
		Providing keys to residents
		Asking staff to knock before entering a room
Property	Lack of personalised environments	Offering residents to "personalize" their own space with items brought from home
	Loss of money and valuables	Asking residents to leave valuables and cash with care home manager
Safety of residents	Moving around the grounds	Care home tailored security measures, locks on doors
	Strangers entering the care home premises	
Health and wellbeing	Moving into a care home	Processes in place before moving into a care home
	Medication	Information leaflets for individuals moving into the home and their families
	Deprivation of liberty	Staff training

- it provides guidelines how to identify discriminatory practice and how to deal with instances of discriminatory behaviour.

The rest of the website of the same provider was similar to many of the others in the sample, making a commitment to desired outcomes and to values but without express references to "human rights".

Discussion. This research was inspired by the UNGPs, particularly the requirement for businesses to publish a statement of commitment to respect human rights throughout their activities. No reference to the UNGPs or the corporate responsibility to respect human rights could be found within the public websites, which suggests that the UNGPs as an instrument may not yet be considered or applied at all or in its full extent by providers, at least in the design of their marketing tools.

Nevertheless, the findings of this research highlight the strong trend of value-oriented marketing and communication by English care home providers. This reflects many providers' perceptions of what potential new service customers and their families, or funders such as local authorities look for when comparing care home vacancies or commissioning their services. Many websites could be interpreted as including public statements of commitment to provide human rights, which will be understandable to the target websites' readers.

Yet, uncertainty persists whether such statements truly and intentionally express commitments to "human rights". The concept of "human rights" is largely absent within the data, and even though some of the care home providers used the word "rights", it is still arguable that this term cannot or must not be understood as a synonym for "human rights". The findings of this research have a range of implications, and various questions arise from them, none of which can be answered within the remits of this paper and thus require either further debate or academic research. Some of the implications and related questions include:

- The need for further research into care home providers' awareness and perspectives on "human" rights and human rights instruments (including the UNGPs) as well as the existence of possible internal human rights policies and implementation mechanisms: despite the heavy use of value-based communication on websites and the opportunity to link many of the values and statements to human rights instruments, care home providers' intentions in this regard or even awareness of the link to human rights cannot be implied from this research. Additionally, the example of a human rights and equality policy highlights the possibility that more than one of the providers internally have similar policies and implementation mechanisms in place. As such, further research investigating the extent of awareness of human rights and instruments such as the UNGPs as well as the possible link between value statements, providers' perceptions of human rights and internal mechanisms is necessary. This might take place in the light of a wider awareness of perceptions of human rights within society and particularly for care home residents and their families.
- The need to further establish the link between person-centred/personalised care and human rights: this research further highlights the need for more clarity regarding the relationship between human rights and person-centred/personalised care and the nature of any statement of commitment to person-centred care in that regard. As the findings show, care home providers seem to make use of the concept of person-centred care within their public profiles. Yet, in the light of the current state of the human rights framework for care home providers, it cannot definitely be concluded that a statement of commitment to person-centred care is synonymously one of a commitment to human rights. This is also highlighted by the example of one home's internal human rights and equality policy, which arguably goes beyond the remits of person-centred care. Such debate would necessarily have to involve a more in-depth discussion regarding the nature of the concepts of person-centred/personalised care and human rights and the need, value, consequences and possible limitations in connecting them more expressly.
- The value of introducing the UNGPs to the care home sector: despite the absence of any express acknowledgement of the UNGPs' corporate responsibility to respect human rights and the potential (and probable) lack of awareness of the principles among care home providers, this research shows that providers are making human rights relevant public

statements of commitment. The question thus arises to what extent introducing the UNGPs to providers, particularly the responsibility to respect human rights and the operational principles to implement this, might be a valuable exercise, keeping in mind that the UNGPs are not a legally binding instrument per se. However, in the light of the relevance of the UNGPs to care home providers, introducing the UNGPs more prominently within this service sector could potentially provide a practical framework for integrating the duty to protect of the Westminster government with an express responsibility for human rights beyond legal and regulatory compliance.

Additionally, future research might draw on the UNGPs "Respect, Protect and Remedy Framework" to evaluate the current state of English laws and regulations regarding the protection of human rights of older residents as well as avenues to access remedy in case of violations. This could usefully include a reflection and integrated discussion of adult safeguarding measures in England.

Conclusion

This paper considered the nature and extent to which large English care home providers publicly communicate any statement of commitment to human rights within their websites, inspired by the UNGPs. It showed that despite the absence of any reference to the UNGPs, care home providers rely on value-based communication in their public facing websites, which may or may not be interpreted to include commitments to respect human rights which are, of course, a fundamental part of safeguarding. This analysis raises various questions and entry points for further investigation. Importantly, it highlights the need for further debate regarding the relationship between person-centred care, personalisation, safeguarding and human rights as well as the possible added value of introducing the UNGPs to the care home sector in England.

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Corresponding author

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Appendix 3: Other publications and public speaking during the PhD

Book review

Emmer De Albuquerque Green, C. (2018) Suzanne Cahill, Dementia and Human Rights, Policy Press, Bristol UK, 2018 238 pp., pbk £24.29, ISBN 13: 978-1-4473-3140-7. *Ageing and Society.* 38(11), 2397-2399.

Blogs

Making Human Rights happen in care homes for older people (December 2018) – Alliance Scotland: **https://www.alliance-scotland.org.uk/blog/opinion/making-human-rights-happen-in-care-homes-for-older-people/**

The Government Must Do More to Protect Human Rights in Care homes (January 2018) – rightsinfo: **https://rightsinfo.org/government-must-protect-human-rights-care-homes/**

CQC emphasises the importance of human rights for high quality care services (March 2018)- Health & Social Care Workforce Blog: **https://blogs.kcl.ac.uk/socialcareworkforce/2018/03/07/cqc-emphasises-the-importance-of-human-rights-for-high-quality-care-home-services/**

PhD related public speaking

07.03.2019 Speaker at the Older People's Health and Social Care Conference: Title of presentation: " "Human rights and what they mean to people working, living in and visiting care homes."

06.03.2019 Speaker at the Margaret Butterworth Care Home Forum: Title of presentation: "Respecting the right to privacy in care homes: Theory and Practice"

24.10.2018 Speaker at MHL Essex and Essex County Council. Title of presentation: "The CQC's human rights approach to regulating"

27.04.2018 Human rights training day for staff in a care home for older people

07.02.2018 Speaker at the annual CQC human rights conference. Title of presentation: "Human rights in care homes"

26.10.2017 Speaker at the Wandsworth Older People's Network Conference. Title of presentation: "Human Rights"

24.11.2016 Speaker at a Mental Health Seminar in Lambeth Council. Title of presentation" "Human rights – what are they and how can they support you in your life?"

09.02.2016 – Human Rights and Older People – AGEUK Conference, London

Appendix 4: Review of the academic literature on human rights and care homes

List of contributions

Title	Author	Year of publication	Country	Type	Journal
Human rights, citizenship and dementia care nursing	Kelly, F. and Innes, A.	2013	UK	Journal article	International Journal of Older People Nursing 8, 61–70
YL v. Birmingham City Council and others	Carr, H., and Hunter, C.	2010	UK	Book chapter	In: Hunter, R., McGlynn, C. and Rackley, E. eds. *Feminist Judgements from Theory to Practice*. Hart, pp. 318-328
Sociology and human rights: what have they got to say about care and dignity?	Ferrie, K.	2010	UK	Journal article	The International Journal of Human Rights, 14(6), pp. 865-879
A randomised controlled trial to evaluate the impact of a human rights based approach to dementia care in inpatient ward and care home settings	Kinderman, P.; Butchard, S.; Bruen A.J.; Wall A., Goulden, N., Hoare, Z.; Jones, C. and Edwards, R.	2018	UK	Journal article	Health Services and Delivery Research, 6(13)
Creating the conditions for self-fulfilment for aged care residents	Brownie, S., and Horstmanshof, L.	2012	Australia	Journal article	Nursing Ethics 19(6), pp.777-7986
Dignity in Long-term care: An application of Nordenfelt's work	Kane, J., and de Vries, K	2017	International	Journal article/Literature review	Nursing ethics, 24(6) pp. 744-751
Informal use of restraint in nursing homes: A threat to human rights or necessary care to preserve residents' dignity?	Oye, C., and Jacobsen, F.	2018	Norway	Journal article	Health,0/00,pp. 1-16
Sex, Dementia, Capacity and Care Homes	Bartlett, P.	2010	UK	Journal article	Liverpool Law Review 31, pp.137-154

Participation of the elderly in socio-cultural life: human rights and inclusive practices under residential care	Riekkinen, M.	2015	Finland	Journal article	Journal of Public Affairs 15(3), pp. 252-267
The Admission of Older People into Residential Care Homes in Argentine: Coercion and Human Rights Abuse	Lloyd-Sherlock, P.; Penhale, B., and Redondo, N.	2018	Argentina/UK	Journal article	The Gerontologist 00(00) 1-9
Human rights-based care for older people	Yates-Bolton, N.	2010	UK	Feature article	Nursing Management, 17(4) pp. 26-27
Ethical Issues in Long-term Care: A Human Rights Perspective	Kusmaul, N., Bern-Klug, M., and Bonifas, R.	2017	USA	Journal article	Journal of Human Rights Social Work 2, pp. 86-97
The Human Rights Act 1998 and care homes	Cooper, J.	2002	UK	Journal aricle	Nursing&Residential Care, Vol.4 No 6
Questionable practices despite good intentions: coping with risk and impact from dementia-related behaviours in care homes	Backhouse, T; Penhale, B., Gray, R., and Killett, A.	2018	UK	Journal article	Ageing and Society, 38, pp.1993-1958
Helping Older People in Residential Care Remain Full Citizens	Sourfield, P.	2007	UK	Journal article	British Journal of Social Work 37, pp. 1135–1152
Introducing an Equal Rights Framework for Older Persons in Residential Care	Jönson,H., and Harnett,T.	2016	Sweden	Journal article	The Gerontologist, 56 (5), 800–806
What does the Human Rights Act add?	Dow, J.	2008	UK	Journal article	Journal of Integrated Care, 16(4), pp.19-21
Dementia and human rights	Cahill, S.	2018	UK	Book	Policy Press
The importance of Human Rights in Residential Care of the Elderly: What do Professional Nurses Know?	Emmer De Albuquerque Green, C.; Costina, A.; Giese, C.; Reuschenbach, B.; Nothhafft, S.,and Fertig.A.	2017	Germany	Book	KFH Munich
Towards Human Rights in Residential Care for Older	Meenan, H., Rees, N., and Doron, I	2016	UK/ International	Book	Routledge: London.

Persons – International perspectives					
Conclusion: from 'residential care' to 'ageing with dignity'	Doron, I., Rees, N., and Meenan, H.	2016	International	Book chapter	In: Meenan, H., Rees and N., Doron, I. (eds) (2016) *Towards Human Rights in Residential Care For Older Persons – International Perspectives*. Routledge: London.
Policies for the aged in the 21st century: more 'structured dependency' or the realisation of human rights?	Townsend, P.	2006	UK	Article	*Ageing and Society*, 26(2), 161-179.
Sexuality in care homes: expression or oppression?	Aylott, J.	2000			*Nursing&Residential Care*. 2(9), 430-435.

Appendix 5: Ethical approval from the Camberwell St Giles Research Ethics Committee 17/LO/0818

NHS
Health Research Authority

London - Camberwell St Giles Research Ethics Committee
Level 3, Block B
Whitefriars
Lewins Mead
Bristol
BS1 2NT

Telephone: 0207 104 8044

29 June 2017

Prof. Jill Manthorpe
Director Social Care Workforce Research Unit
King's College London
Social Care Workforce Research Unit, King's College London
Virginia Woolf Building, 22 Kingsway
London
WC2B 6NR

Dear Prof. Manthorpe

Study title:	**Human rights in care homes: What are the foundations of a 'human rights approach to care' and how could it contribute to enhancing the experience of visiting, living and working in care homes?**
REC reference:	**17/LO/0818**
IRAS project ID:	**222368**

Thank you for your letter of 23 June 2017, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a Sub-Committee of the REC. A list of the Sub-Committee members is attached.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Care Home Advertisement]	Version 1	04 April 2017
Covering letter on headed paper [Covering letter]	Version 1	27 April 2017
Covering letter on headed paper [Caroline_Green_21.06.17_ Response to REC_Covering Letter_Version2]	2	21 June 2017
Interview schedules or topic guides for participants [Topic Guide relatives]	Version 1	04 April 2017
Interview schedules or topic guides for participants [Topic Guide expert participants]	Version 1	04 April 2017
Interview schedules or topic guides for participants [Topic Guides care workers]	Version 1	04 April 2017
Interview schedules or topic guides for participants [Topic Guides care home residents]	Version 1	04 April 2017
Interview schedules or topic guides for participants [Topic Guides care home managers]	Version 1	04 April 2017
IRAS Checklist XML [Checklist_27042017]		27 April 2017
Letters of invitation to participant [Recruitment Email for expert participants]	Version 1	05 April 2017
Other [CV doctoral researcher]		
Other [Follow_upinformation_participants]	1	09 June 2017
Other [Research sites]		
Participant consent form [ConsentForm_generalread (care workers, relatives, residents, care home managers)]	Version 1	04 April 2017
Participant consent form [Consent Form for expert participants]	Version 1	04 April 2017
Participant consent form [Consent Form accessible version]	Version 1	04 April 2017
Participant consent form [Consent Form for participating care homes]	Version 1	04 April 2017
Participant information sheet (PIS) [PIS care home owned and managers]	Version 1	04 April 2017
Participant information sheet (PIS) [PIS care home residents accessible]	Version 1	04 April 2017
Participant information sheet (PIS) [INFORMATION SHEET FOR PARTICIPANTS OF EXPLORATORY EXPERT INTERVIEWS]	2	09 June 2017
Participant information sheet (PIS) [INFORMATION SHEET FOR PARTICIPANTS_care home managers]	2	09 June 2017
Participant information sheet (PIS) [INFORMATION SHEET FOR	2	09 June 2017

PARTICIPANTS_carehomeresidents]		
Participant information sheet (PIS) [INFORMATION SHEET FOR PARTICIPANTS_Careworkers]	2	09 June 2017
Participant information sheet (PIS) [INFORMATION SHEET FOR PARTICIPANTS_Relatives]	2	09 June 2017
Participant information sheet (PIS) [PROJECT INFORMATION SHEET FOR PARTICIPATING CARE HOMES]	2	09 June 2017
Participant information sheet (PIS) [Projectinformationsheet_easy-read]	2	09 June 2017
REC Application Form [SC_Form_27042017]		27 April 2017
Research protocol or project proposal [Caroline Green_Protocol_version 2_09.06.2017]	2	09 June 2017
Summary CV for Chief Investigator (CI) [Chief Investigator Jill Manthorpe's CV]	1	11 April 2017
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Overview of research chart]		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

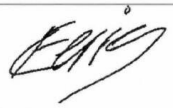
HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

17/LO/0818	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely



PP
Mr John Richardson
Chair

Email:nrescommittee.london-camberwellstgiles@nhs.net

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments

Appendix 6: Text of Project Information Sheet for care homes

PROJECT INFORMATION SHEET FOR PARTICIPATING CARE HOMES

A study on perspectives on the role for human rights for people living and working in care homes

My name is Caroline Green and I am a PhD student at King's College in London. I would like to invite your care home to take part in my PhD research study. Before you decide whether or not your care home will participate in this study it is important for you to understand the purpose of the research and what it will involve. Please take the time to read this information carefully and discuss it with others if you wish. Your care home's participation in the study is completely voluntary.

What is this study about?

Human rights are rights, which we all have because we are human beings. Human rights are a moral as well as a legal issue and have grown in significance for providers of care homes in England over the past years. Under Section 73 of the Care Act 2014, providers of care homes can in some instances be held accountable under national Human Rights law. The Care Quality Commission has been applying a 'human rights approach' to regulating and inspecting care homes since 2014. Still, it is unclear what exactly this means for providers of care and for care home residents. There is a lack of research on this topic, which considers the perspectives of people working, living in and visiting care homes. In my PhD, I would like to engage with you in your capacity as a care home manager, your staff, some residents and some visitors to the care home on this topic. I would like to explore your perspectives on what role human rights could and should play for enhancing the experience of visiting, working and living in care homes. I will be focusing on the issue of privacy of care home residents.

Why you have been invited to take part?

For my PhD study, I am inviting independent care homes in England to participate. I am particularly interested in inviting care homes which provide care and support to people aged 65 years plus and are not specialized on one specific group of people, such as people affected by dementia. It would also be of advantage if your care home were registered with the Care Quality Commission (CQC). I will read your most recent inspection report, but no information provided to me in your care home would be shared with the CQC.

Do you have to take part?

No. Participation is voluntary and you do not have to take part. If you decide on behalf of your care home to take part you will be invited to sign a consent form. You are free to stop your care home's participation any time during the research without a notice period or giving a reason. In this case, research participants within your care home would be given the choice to have their data withdrawn from the study. I would keep data stored up to the point of withdrawal.

What does 'taking part' mean?

If you decide for your care home to take part you will be given this information sheet and a consent form to sign. I will then discuss with you the recruitment procedure of participants within your care home. This will include the discussion of ethical and logistical considerations.
This study includes qualitative interviews with people working, living in and visiting your care home.

I would like to interview around 5 members of your care staff, 4 care home residents and around 4 relatives of residents. The interviews may take place within or outside the care home. I would also like to invite you in your capacity as a care home manager to participate in an interview and you will be provided a separate information sheet for this purpose. Participation in the study will conclude once all interviews have been finished, transcribed and checked by the participants.

Will the information provided be kept confidential?
What is said in all meetings and interviews is regarded as strictly confidential and will be held securely in accordance with the Data Protection Act 1998. Your name, the names of other participants and the name of the organisation/care home will not be revealed and only be known to me and my academic supervisors. All data gathered before, during and after the interviews in your care home will be held on password locked computer files and locked cabinets at King's College London. No data will be accessed by anyone but me and anonymity of the files will be protected by using ID numbers.

What are the potential risks and benefits of taking part?

The information I get from the study will help to share the perspectives of people living, working in, managing and visiting care homes on human rights and the potential role of human rights for a dignified life for older people. This is very valuable and can help to inform the direction of how standards of care are defined. Please note that despite highest standards of confidentiality, there is still a small risk that participants within your care home, and thus the name of your care home will be identified by someone. Further, I will be under the duty to disclose any safeguarding issues, which have come to my attention during the study. This I would first discuss with the participant and yourself in the capacity as care home manager.

What will happen to the results of the study?

I will produce a report summarizing the main findings, which I will be able to send to you. I also plan to disseminate the research findings through publications and conferences.

Who is organising and funding the research?

The research is organised by Caroline Green, a PhD researcher at King's College London. The study has been approved by the Social Care Research Ethics Committee.

What if something goes wrong in the research?

I don’t envisage any major risks associated with taking part in the study. If you have a concern about any aspect of this study, please do not hesitate to contact me:
Caroline Green, k1507085@kcl.ac.uk, Tel: 07447800228 at the
Social Care Workforce Research Unit (SCWRU) King's College London, KCL Strand WC2R 2LS.

In the event that something does go wrong and you are harmed during the research then you may have grounds for legal action for compensation against King’s College London but you may have to pay your legal costs. King’s College London maintains adequate insurance to cover any liabilities arising from the study.
Any complaints can be made to Professor John Abraham, Postgraduate Research Committee Chair, K4L.15, King’s Building, Strand, London, WC2R 2LS, Tel: 02078487412//E-Mail: john.W.abraham@kcl.ac.uk
If you have any questions or would like to volunteer to participate in an interview?
Please contact **Caroline Green, k1507085@kcl.ac.uk, Tel: 07447800228** at the **Social Care Workforce Research Unit (SCWRU) King's College London, KCL Strand WC2R 2LS.**

Thank you for reading this information sheet and for considering taking part in this research.

Appendix 7: Exemplary Project Information Sheet for care home participants (relatives) (customised for every participant group)

INFORMATION SHEET FOR PARTICIPANTS: Relatives

A study on perspectives on the role for human rights for people living and working in care homes

My name is Caroline Green and I am a PhD student at King's College in London. I would like to invite you to take part in my PhD research study. Before you decide whether or not to participate it is important for you to understand the purpose of the research and what it will involve. Please take the time to read this information carefully and discuss it with others if you wish. Your participation in the study is your choice and completely voluntary.

What is this study about?

Human rights are the rights and freedoms we all have simply because we are human beings. They are enshrined in English law, such as the Human Rights Act 1998. The aim of this study is to understand what role human rights could play within a care home setting in providing a dignified life for older people. I am particularly interested in the right to privacy and what this means within a care home setting. There is a lack of research on this topic especially about the views of people working, living in and visiting care homes. This study will involve interviews with different people in care homes, including relatives of care home residents.

Why you have been invited to take part?

For my PhD study, I am inviting people who visit care homes because one or more of their relatives live in a care home. You do not need to have any knowledge about human rights to take part.

Do you have to take part?

No. Participation is voluntary and you do not have to take part. If you decide to take part you will be invited to sign a consent form. You are free to stop any time and to have your information withdrawn without giving a reason. You will be able to check what you have said once our interview has been written up and withdraw information up to 3 months after receiving the write up or an alternative date to be agreed together. I would store your data up to the point of withdrawal.

What does 'taking part' mean?

Participating in this research means that I will interview you once for around one hour. Together we will find a time that is convenient for you to talk and a private place to ensure confidentiality. The interview can take place in your home if this is most convenient for you. On the day of the interview, I will discuss with you the research, answer your questions and invite you to sign a consent form. The interview itself will include questions around your experience of visiting your relative in a care home and on your perspectives on the role of human rights in care homes. In addition to the questions I will ask you to pick a photograph from a set, which best represents your response to a particular question. I will also give you an incomplete sentence and invite you to finish it with your own words. But, you can choose not to join in at any time, have a conversation instead or skip a question without giving a reason. The interview will be audio-recorded subject to your permission. All recordings will be deleted once they have been transcribed.

Will the information provided be kept confidential?

What you say in the interviews is strictly confidential and will be held securely in accordance with the Data Protection Act 1998. Your name and the organisation in which your relative is staying will not be revealed and only be known to me and my academic supervisors.

The information that you share with me will be used to produce a report. Some of what you tell me I may directly quote in my report. Your name or the name of your relative's care home will not appear. Please note that there is still a possibility that other people within the care home or friends and family will be able to identify you by what you have said. If you disclose to me that yourself or someone you know has possibly been a victim of abuse, neglect or other criminal behaviour, I may have the duty to disclose this. However, I would first discuss this with you.

What are the potential benefits of taking part?

Participation will be an opportunity to share with me your perspectives and experiences of visiting your relative in a care home. This hopefully help to shape the future of how older people are cared for in care homes.

What are the potential disadvantages or risks of taking part?

There are no foreseeable risks. The main disadvantage of the study is that you will be giving about one hour or so of your time to take part. Should you experience any distress you can stop the interview any time.

What will happen to the results of the study?

I will produce a report summarizing the main findings, which I will be able to send to you. I also plan to disseminate the research findings through publications and conferences.

Who is organising the research?

The research is organised by Caroline Green, a PhD researcher at King's College London. The study is approved by the Social Care Research Ethics Committee.

What if something goes wrong in the research?

I don't envisage any major risks associated with taking part in the study. If you have a concern about any aspect of this study, please do not hesitate to contact me:

Caroline Green, k1507085@kcl.ac.uk, Tel: 07447800228 at the
Social Care Workforce Research Unit (SCWRU) King's College London, KCL Strand WC2R 2LS.

In the event that something does go wrong and you are harmed during the research then you may have grounds for legal action for compensation against King's College London but you may have to pay your legal costs. King's College London maintains adequate insurance to cover any liabilities arising from the study.

Any complaints can be made to Professor John Abraham, Postgraduate Research Committee Chair, K4L.15, King's Building, Strand, London, WC2R 2LS, Tel: 02078487412//E-Mail: john.W.abraham@kcl.ac.uk

If you have any questions or would like to volunteer to participate in an interview?
Please contact **Caroline Green, k1507085@kcl.ac.uk, Tel: 07447800228** at the **Social Care Workforce Research Unit (SCWRU) King's College London, KCL Strand WC2R 2LS.**

Thank you for reading this information sheet and for considering taking part in this research.

Appendix 8: Project Information Sheet CQC experts

INFORMATION SHEET FOR PARTICIPANTS OF EXPLORATORY EXPERT INTERVIEWS

What is the 'human rights approach to care 'and how could it contribute to enhancing the experience of visiting, living and working in care homes?

My name is Caroline Green and I am a PhD student at King's College in London. I would like to invite you to take part in my PhD research study. Before you decide whether to participate it is important for you to understand the purpose of the research and what it will involve. Please take the time to read this information carefully and discuss it with others if you wish. Your participation in the study is your choice and completely voluntary.

Content and aims of the PhD study: -

This study considers the 'human rights approach to care' as a potential instrument for realizing a dignified life for older people living in care homes. Such approach has been developing on various levels, including in academia and policy. Yet, the exact meaning and content of such an approach for the purposes of care practice is under-researched. This PhD study aims to clarify the theoretical foundations and practical application of the human rights approach to care for care home residents and providers of care in care homes.

The study consists of three phases, involving a theoretical engagement with the subject matter, an analysis of the Care Quality Commission's (CQC) publicly available documents and interviews with individuals living, working in and visiting care homes. The CQC documents to be analysed will be: 1: Documents outlining the CQC's understanding of the human rights approach and 2: Care home inspection reports selected on the basis of pre-determined criteria. Exploratory interviews with CQC's inspectors at the outset of the research will ensure that relevant documents are captured.

Reasons for you having been approached by the researcher: -

As part of my PhD study, I have chosen to engage with the CQC's understanding and application of the human rights approach to care within its inspection mechanisms of care homes. My primary data source for this purpose will be publicly available CQC documents and inspection reports. Before collecting and analysing this data, I would like to speak to individuals employed by the CQC to inspect care homes or in any other capacity or to individuals external to the organisation who have knowledge about the CQC's human rights approach.

Please note, there will be no link between the care home inspection reports being chosen for analysis, any care homes participating in the study and you in your possible role as CQC inspector.

Voluntary participation:-

Participation is voluntary and you do not have to take part. If you decide to take part you will be invited to sign a consent form. You are free to stop your participation any time and to have your information withdrawn without giving a reason. Please note that the information you provide is for informative purposes. However, some of what you say in the interview may be re-produced in reports or other publications. You can withdraw any information up to three months (or an alternative date which we agree on) after receiving your interview transcript per E-Mail. Your data would be stored up to the point of withdrawal.

Participating in the research as an expert respondent:-

Your involvement in the research will be in your professional capacity as CQC inspector, an employee with the CQC or as someone with knowledge about the CQC's human rights approach. It will consist of one interview with me, lasting around one hour at a date, time and

place of your choosing. The interview will follow a topic guide, which evolves around the development and meaning of the CQC's human rights approach to regulating social care services. The interview will be audio recorded using a recording device subject to permission. Interviews will be transcribed and kept on a password protected file on a University computer at King's College London. The audio-recording will then be destroyed.

Confidentiality:-

What is said in the interviews is regarded as strictly confidential and will be held securely in accordance with the Data Protection Act 1998. Your name will not be revealed. Please note that because of the referral sampling strategy and the small sample size there is a risk that your participation in this research may be known to some people in your organisation and you may be identifiable for the information you have provided me.

Potential benefits of taking part:-

The study may not benefit you personally. I hope the publications produced because of this work will be of use to the CQC and add to knowledge about this topic.

Potential disadvantages or risks of taking part:-

There are no foreseeable risks. The main disadvantage of the study is that you will be donating around one hour your time to take part.

Dissemination of results:-

I will produce a report summarizing the main findings, which I will be able to send to you. I also plan to disseminate the research findings through publications and conferences.

Project organisation:-

This project is organised by the PhD researcher Caroline Green at King's College London. The study has been approved by the Social Care Research Ethics Committee.

What if something goes wrong in the research?

I don't envisage any major risks associated with taking part in the study. If you have a concern about any aspect of this study, please do not hesitate to contact me:

Caroline Green, k1507085@kcl.ac.uk, Tel: 07447800228 at the
Social Care Workforce Research Unit (SCWRU) King's College London, KCL Strand WC2R 2LS.

In the event that something does go wrong and you are harmed during the research then you may have grounds for legal action for compensation against King's College London but you may have to pay your legal costs. King's College London maintains adequate insurance to cover any liabilities arising from the study.

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If you have any questions or would like to volunteer to participate in an interview?
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Social Care Workforce Research Unit (SCWRU) King's College London, KCL Strand WC2R 2LS.

Thank you for reading this information sheet and for considering taking part in this research.

Appendix 9: Exemplary consent form

CONSENT FORM FOR INTERVIEW PARTICIPANTS

Human rights in care homes study

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

I confirm that I understand that by ticking each box I am consenting to this element of the study. I understand that it will be assumed that unticked boxes mean that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element I may be deemed ineligible for the study.

Please tick or initial

1. I confirm that I have read and understood the participant information sheet dated XX.XX.XXX version X, for the above study. I have had the opportunity to consider the information and asked questions which have been answered satisfactorily. ☐
2. I understand that my participation is voluntary. I understand I am able to withdraw interview data anytime up to two weeks after I have received the transcript of my interview. ☐
3. I consent to the processing of my personal information for the purposes explained to me. I understand that such information will be handled in accordance with the terms of the UK Data Protection Act 1998. ☐
4. I understand the interview will be anonymous and my name will not be used in any publications or outputs from the study. I understand that due to the small number of interviewees, there is a small chance I could be identifiable. ☐
5. I understand that what I say may be used to produce presentations, reports and journal articles. In some or all of these, I understand that some of what I have said will be directly quoted but my name will not appear. ☐
6. I consent to my interview being audio recorded. ☐
7. I understand that the researcher has a duty to disclose any information about abuse, neglect or other adult safeguarding concerns. ☐

_____ _____ _____

Name of Participant Date Signature

I have explained the study and answered any questions from the participant honestly and fully

_____ _____ _____

Name of Researcher Date Signature

Appendix 10: Exemplary topic guide for semi-structure interview (here care workers)

EMPIRICAL RESEARCH IN CARE HOMES PARTICIPANT TYPE: **Care workers** **Outline of the interview process, topic guide and interview techniques**			
Stage of interview appointment	**Topic**	**Tools**	**Notes**
1: INTRODUCTION/ CONSENT	Introduction of researcher		
	Introduction of research project/time for participant's questions about the research		This includes an introduction to the various interview techniques. The researcher will check with the participant whether they feel comfortable to use them or would prefer a conversation instead.
	Consent to research via signing consent form recorded by researcher		
2: RECORDING OF PERSONAL DATA	Respondent's name		The socio-demographic information will be recorded on one sheet per respondent. Each respondent will receive an ID number to be kept separately from the socio-demographic information sheet. Field notes will not reveal names or other personal information, only ID numbers.
	Gender		
	Age		
	Ethnicity		
	Nationality		
	Respondent's job title		
	Part-time, full-time employment		
	Amount of time employed by care home		
	Amount of time employed as care worker		
	Level of professional training		
	Human rights training received in the past		
3:INTERVIEW			

	What first comes into your mind when you hear the words ‘human rights’?	Photo-elicitation/conversation	
	How do you think human rights are relevant for care in care homes?		
	Has there been a time at your workplace where you have thought about human rights?		
	Has there been a time where you have faced a human rights related dilemma?		
	Considering any of the topics or one of your choosing, what emotions do they invoke in you?	Emotional touchpoint (,human rights and my profession/right to privacy/right to personal liberty)	Participant can choose one touchpoint or create one by her/his self
	How do you define ‘good care’?		
	Please tell me of a time where you felt like a care related dilemma was resolved well in regard of any of the topics laid out or any of your choosing	Storytelling (touchpoints will be laid out)	
	What do you think was good about the way this dilemma was resolved?	Storytelling	
	What helped you or the person in the story to resolve the dilemma?	Storytelling	
	Please tell me of a time when you or someone you know felt you/they were facing a care related dilemma and you/them found it hard to find hard to find a solution	Storytelling	
	How do you think could any of the principles laid out on the table be helpful to find a solution with a positive outcome to a comparable dilemma?	FAIR principles (Facts, Analysis of rights a stake, Identification of responsibilities, Review of actions) laid out on table	At this point, the researcher will introduce the principles of the ,FAIR tool’ with short explanations to the participant
	Please finish this sentence: Integrating human rights into my work more closely makes me feel... because.... or provide your own sentence how you feel integrating human rights	Sentence starter/Photo-elicitation	Participant is given the option between sentence starter, a conversation or choosing an image

	more closely into the care home		
3: Finish			
	Is there anything else you would like to tell me? Do you have questions?		
	Thank you for participating		
	Offer to provide sheets with telephone numbers/helpline numbers		In case the participant showed signs of distress